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The nursing contribution to chronic disease management: a whole systems approach

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Acronyms

BMI	Body Mass Index
BP Blood	Blood Pressure
CDM	Chronic Disease Management
CHD	Coronary Heart Disease
CM	Case Management
COPD	Chronic Obstructive Pulmonary Disease
COREC	Central Office for Research Ethics Committees
CRC	Cardiff Research Consortium
DAFNE	Dose Adjustment for Normal Eating
DCSF	Department for Children, Schools and Families
DESMOND	Diabetes Education and Self Management for Ongoing and Newly Diagnosed
DM	Disease Management
DNA	Do Not Attend
DSN	Diabetes Specialist Nurse
ECM PF	"Every Child Matters" Policy Framework
EMIS	Egton Medical Information Systems
ED (US)	Emergency Department (US)
ESN	Epilepsy Specialist Nurse
FEV1	Forced Expiratory Volume in 1 second
FTE	Full Time Equivalent
GMS	General Medical Services
GP	General Practitioner
GPN	General Practice Nurse
HbA1C	Glycosylated haemoglobin A1C
HDL	High-Density Lipoprotein
HODaR	Health Outcomes Data Repository
INR	International Normalised Ratio
ISOFT	Specialist health information technology provider

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LA	Local Authority
LDL	Low-Density Lipoprotein
LHB	Local Health Board
LTC	Long Term Condition
MDT	Multidisciplinary Team
MI	Myocardial Infarction
MS	Multiple Sclerosis
NICE	National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
NRES	National Research Ethics Service
NSF	National Service Framework
NVIVO	Qualitative Research Software
QOF	Quality and Outcomes Framework
QoL	Quality of Life
PARR	Patients At Risk of Readmission
PBC	Practice Based Commissioning
PCT	Primary Care Trust
PE	Physical Education
PDS	Parkinson's Disease Society
PSA	Public Service Agreement
RCT	Randomised Controlled Trial
SD	Standard Deviation
SDO	Service, Delivery and Organisation
SOA	Super Output Area
TAU	Treatment As Usual

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Executive Summary

Background

Transforming the delivery of care for people with Long Term Conditions (LTCs) requires understanding about how health care policies in England and historical patterns of service delivery have led to different models of chronic disease management (CDM). It is also essential in this transformation to analyse and critique the models that have emerged to provide a more detailed evidence base for future decision making and better patient care. Nurses have made, and continue to make, a particular contribution to the management of chronic diseases. In the context of this study, there is a particular focus on the origins of each CDM model examined, the processes by which nursing care is developed, sustained and mainstreamed, and the outcomes of each case study as experienced by service users and carers.

Aims

To explore, identify and characterise the origins, processes and outcomes of effective CDM models and the nursing contribution to such models using a whole systems approach

Methods

The study was divided into three phases:

Phase 1: Systematic mapping of published and web-based literature.

Phase 2: A consensus conference of nurses working within CDM. Sampling criteria were derived from the conference and selected nurses attended a follow up workshop where case study sites were identified.

Phase 3: Multiple case study evaluation

Sample: 7 case studies representing 4 CDM models. These were: i) public health nursing model; ii) primary care nursing model; iii) condition specific nurse specialist model; iv) community matron model.

Methods: Evaluative case study design with the unit of analysis the CDM model (Yin, 2003):

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- semi-structured interviews with practitioners, patients, their carers, managers and commissioners
- documentary analysis
- psycho-social and clinical outcome data from specific conditions
- children and young people: focus groups, age-specific survey tools.

Benchmarking outcomes: Adults benchmarked against the Health Outcomes Data Repository (HODaR) dataset (Currie *et al,* 2005). Young people were bench-marked against the Health Behaviour of School aged Children Survey (Currie *et al,* 2008).

Cost analysis: Due to limitations in the available data, a simple costing exercise was undertaken to ascertain the per patient cost of the nurse contribution to CDM in each of the models, and to explore patterns of health and social care utilisation.

Analysis: A whole system methodology was used to establish the principles of CDM. **i) The causal system** is a "network of causal relationships" and focuses on long term trends and processes. **ii) The data system** recognises that for many important areas there is very little data. Where a particular explanatory factor is important but precise data are lacking, a range of methods should be employed to illuminate each factor as much as possible. **iii) The organisational whole system** emphasises how various parts of the health and social care system function together as a single system rather than as parallel systems. **iv) The patient experience** recognises that the whole system comes together and is embodied in the experience of each patient.

Key findings

While all the models strove to be patient centred in their implementation, all were linked at a causal level to disease centric principles of care which dominated the patient experience.

Public Health Model

- The users (both parents and children) experienced a well organised and coordinated service that is crossing health and education sectors.
- The lead school nurse has provided a vision for asthma management in school-aged children. This has led to the implementation of the school asthma strategy, and the ensuing impacts including growing awareness, prevention of hospital admissions, confidence in schools about asthma management and healthier children.

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Primary Care Model

- GP practices are providing planned and routine management of chronic disease, tending to focus on single diseases treated in isolation. Care is geared to the needs of the uncomplicated stable patient.
- More complex cases tend to be escalated to secondary care where they may remain even after the patient has stabilised.
- Patients with multiple diagnoses continue to experience difficulty in accessing services or practice that is designed to provide a coherent response to the idiosyncratic range of diseases with which they present. This is as true for secondary care as for primary care.
- While the QOF system has clearly been instrumental in developing and sustaining a primary care nursing model of CDM, it has also limited the scope of the model to single diseases recordable on a register, rather than focus on patient centred care needs.

Nurse Specialist Model

- The model works under a disease focused system underpinned by evidence based medicine exemplified by NICE guidelines and NSF's.
- The model follows a template drawn from medicine and sustainability is significantly dependent on the championship and protectionism offered by senior medical clinicians.
- A focus on self-management in LTCs gives particular impetus to nurse-led enablement of self-management.
- The shift of LTC services from secondary care to primary care has often not been accompanied by a shift in expertise.

Community Matron Model

- The community matron model was distinctive in that it had been implemented as a top down initiative.
- The model has been championed by the community matrons themselves, and the pressure to deliver observable results such as hospital admission reductions has been significant.
- This model was the only one that consistently resulted in open access (albeit not 24 hours) and first point of contact for patients for the management of their ongoing condition.

Survey Findings

Compared to patients from our case studies those within HODaR visited the GP, practice nurse or NHS walk-in centres more, but had less home visits from nurses or social services within the six weeks prior to survey. HODaR

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patients also took significantly more time off work and away from normal activities, and needed more care from friends/ relatives than patients from our study within the last six weeks. The differences between the HODaR and case study patients in service use cannot easily be explained but it could be speculated when referring to the qualitative data that the case study patients are benefiting from nurse-led care.

Cost analysis –

The nurse costs per patient are at least ten times higher for community matrons conducting CDM than for nurses working in other CDM models. The pattern of service utilisation is consistent with the focus of the community matron role to provide intensive input to vulnerable patients.

Conclusions

Nurses are spearheading the kind of approaches at the heart of current health policies (Department of Health, 2008a). However, tensions in health policy and inherent contradictions in the context of health care delivery are hampering the implementation of CDM models and limiting the contribution nurses are able to make to CDM. These include:

- data systems that were incompatible and recorded patients as a disease entity
- QOF reinforced a disease centric approach
- practice based commissioning was resulting in increasing difficulties in cross health sector working in some sites
- the value of the public health model may not be captured in evaluation tools which focus on the individual patient experience.

Recommendations

Commissioners and providers

1. Disseminate new roles and innovations and articulate how the role or service fits and enhances existing provision.

2. Promote the role of the nurses in LTC management to patients and the wider community.

3. Actively engage with service users in shaping LTC services to meet patients' needs.

4. Improve the support and supervision for nurses working within new roles.

5. Develop training and skills of nurses working in the community to enable them to take a more central role in LTC management.

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6. Develop organisations that are enabling of innovation and actively seek funding for initiatives that provide an environment where nurses can reach their potential in improving LTC services.

7. Work towards data systems that are compatible between sectors and groups of professionals. Explore ways of enabling patients to access data and information systems for test results and latest information.

8. Promote horizontal as well as vertical integration of LTC services.

Practitioners

1. Increase awareness of patient identified needs through active engagement with the service user.

2. Work to develop appropriate measures of nursing outcomes in LTC management including not only bureaucratic and physiological outcomes, but patient-identified outcomes.

Implications of research findings

1. Investment should be made into changing patient perceptions about the traditional division of labour, the nurses' role and skills, and the expertise available in primary care for CDM.

2. Development and evaluation of patient accessible websites where patients can access a range of information, their latest test results and ways of interpreting these.

3. Long-term funding of prospective evaluations to enable identification of CDM outcomes.

4. Mapping of patient experience and patient satisfaction so that the conceptual differences between these two related ideas can be demonstrated.

5. Development of appropriate measures of patient experience that can be used as part of the quality outcome measures.

6. Cost evaluation/effectiveness studies carried out over time that includes national quality outcome indicators and valid measures of patient experience.

7. The importance of whole system working needs to be identified in the planning of services.

8. Research into the role of the health visitor in chronic disease management within a public health model.

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The Report

1 Background

Planning for this research began in 2005. At that time the management of LTCs dominated the United Kingdom (UK) health policy agenda. During 2004/5 the Department of Health (DH) published a number of policy documents on the management of LTCs (Department of Health, 2004a; Department of Health, 2005a; Department of Health, 2005b). Lewis & Dixon (2004) had recently published the case for rethinking CDM in the British Medical Journal. Boaden *et al* (2005) had published the early results of their evaluation of Evercare in the UK.

The accumulated evidence at the time of developing the proposal indicated that CDM challenged many of the assumptions that underpin the acute medical model of care dominant in western health care delivery systems (Abel-Smith, 1994; Department of Health, 2004b; Harwood *et al,* 2004). The consequences of a traditional focus on acute care includes clinical effectiveness being defined through access to medical technology, rather than through increasing the health capacity of the patient, family and community, despite evidence that health technology has only a marginal impact on health gain (Abel-Smith, 1994; McKee *et* al, 1998; Wanless, 2002). In addition an acute medical model emphasises medical rather than nursing (Cullum *et al,* 2005) or patient determined outcomes and is incongruent with the discourse of patient centredness in LTCs (Department of Health, 2005b). Reducing mortality from chronic illness and maintaining health among those experiencing long-term conditions requires engagement with lifestyle factors (Wanless, 2002). This is difficult to address in many acute care settings which are characterised by episodic and time limited engagement with the patient focused increasingly on early discharge back into the community.

1.1 Previous approaches to chronic disease management

Most of the research and guidelines on chronic disease have focused on singular diseases, e.g. hypertension, diabetes, asthma. However, there is increasing awareness that the patient's experience of chronic disease is cumulative. Estimates vary but there is evidence that up to two-thirds of patients with one of the five most common chronic diseases also have two or more chronic conditions and typically patients in the top 10% of service users have four or more chronic conditions (Department of Health, 2004b). There is increasing concern that focusing research on singular

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diseases is impeding our ability to care effectively for people with multiple conditions. For instance the acceleration of guideline-driven medication for a specific disease has excluded research on the long-term impacts of these regimens for people with multiple conditions and multiple drug therapies giving rise to the conclusion that what is good for the disease may not be best for the patient (Tinetti *et al,* 2004). This type of evidence underpins the importance of identifying how to implement systems which can support individualised care negotiated in the context of expert provision.

1.2 Nursing and long-term conditions

Nursing has long been recognised as having a key role to play in helping people to manage long-term conditions (Audit Commission, 1999; Kratz, 1978). However, there is evidence of a lack of proactive engagement with the client groups' needs (Kratz, 1978; Gibbon; 1994; Wilson *et al,* 2006) and until recently nursing in the UK has not fully realised its potential to meet the needs of the chronically ill (Nolan and Nolan, 1995; English National Board, 1997). There is a wealth of literature which testifies to the subjugation of nursing to the acute medical model (Davies, 1995; Warner *et al,* 1998) and this may help explain an unrealised nursing contribution in caring for those affected by LTCs (Benner and Wrubel, 1989). The global focus on chronic disease and consequent examples of innovative practice elsewhere (World Health Organisation, 2002) combined with a succession of national policies focusing on CDM has provided a catalyst and legal impetus (Department of Health, 2004c) for UK nurses to address their contribution to CDM. Evidence indicates improved outcomes from an enhanced nursing role via specialist nurses who provide care and manage the needs of clients within a specific condition group (Frich, 2003), or where generalist nurses are able to enhance their skills and focus systematically on particular groups of patients (Colledge *et al*, 2003). Theoretical models of nursing within chronic disease have also been developed (Corbin and Strauss, 1992; Miller, 1992) suggesting a potentially useful contribution towards nursing knowledge (Burton, 2000). Despite these innovations, one of the most significant influences on nursing in the UK is the adoption of nursing models from the United States (Department of Health, 2004a). The Evercare model of case management (Department of Health, 2004b) has the role of Advanced Primary Nurse (Department of Health, 2003a) as a key feature. However, the transfer of this model to the UK setting did not replicate the patient outcomes demonstrated in the US in relation to reduced demand for acute hospital care although improvement in some outcomes such as patient and carer satisfaction was found (Boaden *et al,* 2006; Gravelle *et al,* 2007). The expanded nursing role such as Evercare or the currently evolving role and competencies of the community matron (Department of Health, 2005d; Department of Health, 2006a) are designed to meet the needs of those most vulnerable with complex morbidities. However, this group of patients with highly complex needs are a minority of those affected by long-term conditions. The majority of people with chronic illness are able to self-care

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with carefully targeted professional input, and other US models piloted within the UK such as Kaiser Permanente, Pfizer Health Solutions, Pursuing Perfection (Department of Health, 2004b) and the Expert Patient Programme (Rogers *et al.,* 2006; Wilson, 2008) have the facilitation of patient self-management as a key aim (Department of Health, 2005c). The wide and varied roles in nursing, midwifery and health visiting such as school nursing, practice nursing, community midwife, and smoking cessation nurse lend themselves to a broad interface with client groups vulnerable to or living with a variety of long-term conditions, with a potentially significant role within any part of the LTC Model (see figure 1, section 1.3) recommended by the Department of Health, ranging from health promotion to caring for those with highly complex needs.

1.3 The long-term conditions model

During the life of this research project health care policy has moved on. While CDM and LTC remain important policy drivers within the NHS as figure 1 indicates, policy initiatives have shifted from the implementation of specific CDM models to the identification of the principles of good practice in managing LTC (Department of Health, 2007a; Skills for Health, 2008) and to commissioning services which will support a diversity of LTC models based on the principles of good practice identified in the policy literature through the DH World Class Commissioning Programme (Department of Health 2007b).

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Figure 1 Long-term conditions model

Level 3: Case management

Requires the identification of the very high intensity users of unplanned secondary care. Care for these patients is to be managed using a community matron or other professional using a case management approach, to anticipate, co-ordinate and join up health and social care.

Level 2: Disease-specific care management

Involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways, such as the National Service Frameworks and Quality and Outcomes Framework.

Level 1: Supported self care

Collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively.

(Department of Health 2005c)

The policy shift that has taken place during the life of this research testifies to the complexities encountered in shifting the focus of care to meeting the needs of people with, or at risk of experiencing, LTC. Transforming the delivery of care for people with LTC requires the capacity to analyse the context, identify appropriate solutions and manage sustained change within the system. In order to bring about sustained change capable of mainstreaming the principles of service delivery embedded in the policy guidelines we need to understand how the UK historical patterns of service delivery affect outcomes from care. Without this type of analysis we risk reproducing structural characteristics of service delivery in new forms rather than transforming the way care is delivered (Flood, 1994).In the research presented here the nurses' role in CDM is analysed in the context of a whole systems approach (Procter *et al.,*2000) to health care delivery. This approach balances individualised responses to patient and carer identification of needs and desired outcomes with expert evidence based models of professional care. Four models of nursing care are analysed: i) the public health nursing model; ii) the primary care nursing model; iii) the condition specific nurse specialist model; iv) the community matron model; within a whole systems framework and evaluated against the principles of good practice in caring for people with LTC in order to identify the varied contribution of nursing to CDM and the contexts which promote effective nursing practice.

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1.4 Aims and objectives of the study

Aim of study

To explore, identify and characterise the origins, processes and outcomes of effective CDM models and the nursing, midwifery and health visiting[1] contributions to such models using a whole systems approach.

Objectives

The objectives were organised to reflect the origins, processes and outcomes of CDM:

1. Develop a systematic mapping of the literature of the nursing, midwifery and health visiting role in CDM.

2. Identify the range of CDM models used nationally.

3. Explore the user, carer and professional experience of CDM models.

4. Explore the characteristics of an enabling context for CDM.

5. Identify, measure and profile outcomes of a representative range of CDM models.

6. To compare the costs of delivering different CDM models, and explore patient health and social care utilisation.

7. Define the characteristics and mechanisms required for effective nursing, midwifery and health visiting involvement within CDM.

The aim and objectives of the study are underpinned by the central tenet that nursing, midwifery and health visiting are characterised by a focus on the patient perspective and caring for the person through their lived experience of chronic disease within a multi-professional environment. Increasing scientific understanding of the factors associated with health highlights the importance of incorporating theories of public health and health promotion, across the lifespan, into the practice of nursing. The inclusion of public health and health promotion practices challenges many aspects of nursing specifically and health care generally. Throughout the study the central tenet and challenges facing nursing will be' tested' through the constant comparison of data from each of the phases.

[1] Please note that whilst at the start of this study the aim was to include midwives and health visitors, it became apparent as the study proceeded that these professional groups do not have significant roles in CDM. The overarching title of the report has therefore dropped the terms midwife and health visitor.

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1.5 The structure of this report

The report is divided into 9 sections. Following this introductory section, an account of the methodology is provided. In sections 3 and 4 findings from the systematic mapping of evidence and the consensus conference are presented. Sections 5 and 6 describe the findings from the case studies and surveys. In section 7 the economic analysis is provided including an account of the challenges and limitations of this part of the research. This is followed by a discussion of the findings and overview of the limitations of the study. Finally, in section 9 conclusions are drawn and a series of recommendations for practitioners, providers, commissioners, policy makers and researchers are identified.

1.6 Summary

The study commenced at a time of a number of policy initiatives around the management of LTCs. Nursing's key role within CDM has long been recognised and was explicit within many of the policy initiatives. However, there is a dearth of evidence around the impact of the nursing contribution to CDM, how historical patterns of service delivery affect outcomes of care, and how care is shaped as part of a whole system. The aim of the study was therefore to explore and identify origins, processes and outcomes of effective CDM models and the nursing contribution to these models using a whole systems approach.

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2 Methodology

This study has been conducted within the theoretical framework of whole systems analysis. This decision was taken on the grounds that in order to understand the nursing contribution to a service, we have to explore, analyse and understand the context in which nursing takes place and the complex relationships between systems of policy, health, social care and education provision as well as organisational shifts and structures. The inter-play between these systems has an overall effect on how the patient experiences care and this became an increasingly important focus of the study as it progressed.

Taking a whole systems approach is about gathering local intelligence to understand the impact of changes in one part of the system on everything else. It therefore fits very closely with the explanatory case study methodology used within this research. An understanding of how the whole system works can then help develop understanding about how to plan and deliver services and use resources to make sure that people get the services they need, delivered to a high quality and in a sustainable way. Using this approach has enabled us to identify not only the contribution made by nurses to CDM in the NHS, but also the systemic impact of the nursing contribution, including where it might make most impact in terms of health outcomes and quality of life, but also where it might be dysfunctional within the system of care provision.

2.1 A whole systems approach

There is no one overriding approach to whole systems methodology, instead the approach is evolving in response to the problems of delivering high quality, sustainable services within the resources available to the local health and social care economy. The approach we adopted is based on the work of Kendrick and Conway (2003) who used whole system thinking to model delayed discharge in Scotland. This study identified four principal perspectives in producing a whole systems analysis, which were found useful in explaining to stakeholders what they were trying to achieve. Our analysis focused more at the nurse/patient interface. Kendrick and Conway (2003) have identified four principal perspectives on the whole system:

i) The causal system is a "network of causal relationships … which points towards trends and processes unfolding gradually over the long term". It shifts attention away from events towards the unfolding of slow gradual processes over time, which Senge (1990) identifies as posing the greatest threat to our survival. This focus fits with the National Institute of Health Research service delivery and organisation programme (NIHR SDO) concern to understand model origins.

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ii) The data system recognises that for many of the most important areas of the whole system we have very little data. The structure of explanation cannot be determined by the availability of systematic data, where a particular explanatory factor is important but precise data are lacking, we must use every means at our disposal to do that factor justice. This fits with the case study approach used in this study, data that was systematically collected locally was used and analysed to identify the origin, process and outcomes of CDM but also what it could not tell us.

iii) The organisational whole system is by far the most common context in which whole systems are analysed. The emphasis is on making the various parts of the health and social care system function together as a single system rather than as parallel systems. The organisational perspective was relevant to this study in two ways. Firstly, the analysis is only worthwhile if it makes a practical contribution to improving the contribution nursing (the largest NHS workforce) can make to improving CDM (recognised by many as the biggest challenge facing the NHS). Secondly, the extent to which the health and social care system fails to function as a whole system may form part of the explanation about the level of contribution nurses are found to make to CDM.

iv) The patient experience of the whole system recognises that the whole system comes together and is embodied in the experience of each individual patient. The individual experience, therefore, provides a microcosm of the level of service integration achieved locally and provides evidence of model outcomes. Since this study was first proposed in 2006 the Darzi Report (Department of Health, 2008a) has emphasised the significance of the patient experience as a component of quality in the delivery of NHS services, therefore this aspect of the whole systems approach took on increasing relevance as the study progressed.

Our approach built on earlier research, which modelled the dynamic interaction between patients, carers and service utilisation (Pearson *et al,* 2004). In each case study used in this research we have shown how the local health and social care system impacts on patient and carer behaviour in relation to service utilisation and the actual and potential contribution of nursing in mediating patient and carer behaviour in order to describe and explain the patient experience and quality of life for a range of patient and client groups.

In this study we drew together the unifying evidence which suggested that although there are important differences between models required for CDM and prevention, there are a greater number of common factors (Wagner and Groves, 2002). The focus on service utilisation as one

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outcome indicator in whole systems methodology is appropriate to the Department of Health concerns to reduce hospital utilisation among this group of patients. However, reducing hospital utilisation within the current fragmented system of care delivery is unlikely to bring about the changes required to secure health gains for this population. To be effective guidelines on CDM recommend pro-active, integrated, individualised and person-centred care models which address the specific mix of physiological and psychosocial problems presented by each patient and which locate the patient's role in managing their own care, within the context of individual, family and local service resources (Norris *et al*, 2003).

Nursing has a long history of theorising individualised care (Kratz, 1978), but it is less successful at implementing individualised care in practice (Suohnen *et al*, 2002). There is increasing emphasis on care coordination both in CDM and in nursing, but nursing models of care (like CDM models) struggle to extend understanding of care provision to include pro-active provision across the local system and to negotiate individualised provision in this context. This formed the focus of our analysis and, in particular, the effect of these models on the patient experience.

2.2 Methods

We used a whole system methodology to establish the principles of CDM drawn from the evidence base from each tier in the long-term conditions model (see 1.3), and to use theoretical sampling to select cases where nurses are central to CDM and correspond to the principles identified. In each case the focus for data collection and analysis was on:

i. identifying similarities and differences between the principles and the cases

ii. identifying contextual drivers and barriers to implementation of the principles

iii. using the patient/carer experience as a representation of the practice of the whole system

iv. locating the role of the nurse within the context of the delivery system and within the patient experience of care

v. cost evaluation of the different models of CDM

vi. benchmarking data was used to indicate the typicality of the patients to the general population of patients and therefore facilitate generalisation.

2.3 Phase 1: Scoping Exercise

We conducted a nationwide scoping exercise and systematic mapping of the literature to capture examples of best and innovative nursing practice in CDM. The aim was to identify, map and evaluate models of CDM

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involving nurses, midwives or health visitors. The mapping sought to answer the following questions:

i. what examples are there of nurses working in CDM?
ii. what is the nature of their role (e.g. traditional nursing role/ taking on tasks previously done by doctors)?

iii. what are the effects of nurses working in CDM?

iv. what are the barriers and facilitators to nurses working in CDM?

v. what is the patient perspective on the role of nurses in CDM?

2.3.1 Inclusion criteria

We included all study designs including systematic reviews. This included studies that: evaluated the provision of chronic disease care by nurses, midwives or health visitors (e.g. outcome studies) and measured relevant outcomes such as health related variables, patient satisfaction and cost; or studies that provided information on the views of service users and providers and identified barriers and facilitators to nurse, midwife and health visitor involvement and provision of CDM (e.g. views studies). We only included studies that had a specific focus on service provision/receipt by nurses, midwives and health visitors and excluded studies concerned with experiences of chronic illness in general. We also excluded some long-term conditions such as cancer or mental illness that may not be amenable to CDM. As current health policy in the UK has been heavily influenced by models of CDM that have originated elsewhere, in particular the US, we included international studies that were considered to be relevant to the UK health service. However CDM represents an increasingly global challenge for health care systems (Murray and Lopez, 1997). The globalisation of health care needs and issues has profound implications for nursing research, clinical practice and theory (Davidson *et al*, 2003), to the extent where nursing theory and practice development needs to be grounded in an understanding of nursing as a globalised health workforce.

Nursing in the UK is likely to benefit by critically considering how international models, beyond those developed in the US, may enhance the nursing response to CDM. It is likely to be beneficial to consider models from other health care economies that have a delivery system that is closer to the UK model. The application of lessons learned from countries such as Japan and Scandinavia, may offer specific strategies to respond to key challenges of CDM.

2.3.2 Search Strategy to identify literature

The search strategy was designed by an experienced information scientist to be highly sensitive and used a mixture of free text terms and MeSH headings. We searched for English language studies using the following electronic databases: PubMed, CINAHL, AMED, BNI, DH Data, Kings Fund,

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Psychinfo, HMIC, NRR, ERIC and NTIS from January 1996 to April 2006. In addition we checked reference lists. Full details of databases searched and search terms used can be seen in Appendix 1. The initial searches generated over 12,000 records which were downloaded into Endnote. To reduce this to a more manageable datapool we then ran more specific searches within Endnote which reduced the number of records to 4724. Titles and abstracts of these records were screened against the inclusion criteria and hard copies of potentially relevant papers were obtained and screened.

2.3.3 Data extraction and evaluation of literature

Studies were categorised as to whether they were an outcome study (e.g. randomised controlled trials (RCT) and other quantitative studies), a study looking at views/experiences (e.g. qualitative studies) or a descriptive study (e.g. surveys). Within each of those broad categories studies were then further classified by type (e.g. systematic review, RCT, controlled study, uncontrolled before/after, cohort, survey, qualitative study, audit, retrospective review, economic analysis etc) and by the type of disease or illness. We also categorised studies according to where they fitted within the long-term conditions model (Department of Health, 2005c) (e.g. health promotion, self-care support/management, high-risk, highly complex needs).

Data were extracted onto a specially designed form. This included information on study type and focus, quality, content of interventions, type of control, participants, type of health professional involved, organisation involved, outcomes measured, results, and barriers and facilitators encountered. As our aim was to 'map' rather than systematically review the literature, and as we envisaged a large number of studies would meet our inclusion criteria, we did not undertake a detailed quality assessment of all papers. Quality assessment was limited to systematic reviews and RCTs as it was envisaged that these would be relied on most heavily when assessing the effectiveness of interventions. Systematic reviews were assessed against the NICE methodology checklist for systematic reviews taken from the NICE methodology guidelines (NICE, 2006). RCTs were assessed using the following criteria:

i. allocation concealment (judged as adequate, inadequate or unclear)

ii. lost to follow up (follow up classified as adequate if 80% or more followed up)

iii. intention to treat analysis

iv. blinding of outcome assessment.

These criteria are those factors associated with bias in RCTs and are similar to those used elsewhere (Higgins and Green 2006). In addition, for all studies, we recorded whether a sample size calculation was reported and whether the study recruited sufficient participants.

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2.3.4 Synthesis of findings

Owing to considerable heterogeneity in the types of studies, participants, interventions and outcomes it was considered to be inappropriate to pool studies in a meta-analysis. Instead data for each study were extracted into a table with an indication of whether the intervention had a positive effect (+), a negative effect (-) or no statistically significant effect (0) on each of the reported outcomes. To identify barriers and facilitators commonly and consistently occurring themes across studies were identified. Views and experiences studies were particularly important for this part of the analysis.

2.3.5 Systematic web site review

A web based systematic search of practice dissemination sites was undertaken prior to the stakeholder conference. It is recognised that web-based databases are an increasingly useful way of disseminating best practice (Gerrish *et al,* 2004) and specific national sites are established for this purpose (e.g. NHS Networks). This method makes efficient use of existing resources and also negates the need for potentially complex research management and governance processes across multiple health care organisations (Howarth and Kneafsey, 2005).

Inclusion criteria

We included all web postings that describe models of CDM involving nurses, midwives or health visitors. The aim of the web site review was to find:

i. examples of nurses working in CDM/LTCs.

ii. what is the nature of their role (e.g. traditional nursing role/ taking on tasks previously done by doctors)

iii. an indication of the effect of nurses working in CDM/LTCs.

iv. an indication of barriers and facilitators to nurses working in CDM/LTCs.

We searched for all potentially relevant descriptions posted on UK official web sites. The web sites included natpact.nhs.uk (specifically "Can Do!" service provision pages and "Supporting people with LTCs" pages) (now the NHS Networks site), Strategic Health Authority sites, Acute, Partnership and Primary Care Trusts sites, all 108 organisations affiliated to the Long Term Medical Condition Alliance (LMCA) (e.g. Multiple Sclerosis Society, PDS, Arthritis Care), professional bodies (e.g. Royal Colleges of Nursing and Midwifery, Community Practitioners' and Health Visitors' Association [CPHVA]), and academic nursing units of higher education institutions.

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2.3.6 Synthesis of findings

A thematic discourse analysis as well as a simple count enabled the research team to scope the types of CDM models currently in place, the local policies and drivers, and the nature of nurse involvement in CDM. The thematic analysis was used as one approach to identify possible exemplars and participants to be invited to participate in the stakeholder consensus conference in the next phase.

2.4 Phase 2: Stakeholder consensus conference

Phase two both complemented and cumulatively added to findings from phase one. Phase two consisted of a stakeholder conference and criteria identification workshop. The stakeholder conference was hosted in London following phase one. It was followed up eight weeks later by a workshop of purposefully selected participants from the conference and the setting up of a virtual panel of international nurse experts in CDM.

2.4.1 Aims of the Conference

A stakeholder conference was hosted following phase one of the study (15 September 2006, Kings Fund, London). The conference functioned as a forum for the presentation and discussion of models of CDM identified in phase one with the aim of reaching a typology of models.

It was confirmed by the COREC that ethics approval was not required to run the conference and workshop.

It was envisaged that the conference would lead to the development of selection criteria for the case study sites through a post-conference workshop of key stakeholders. Specifically the conference aimed to:

i. refine and extend the debate concerning the nursing contribution to models of CDM

ii. capture the temporal dynamics of the nursing contribution to the evolving models of CDM

iii. contextualise the international models of CDM for the NHS context.

2.4.2 Theoretical Context

Consensus methodology is useful in gaining the insights of experts, determining the extent of agreement about a given issue (Jones & Hunter, 1995), and providing a bridge between practice and published studies research. However there has been comparatively little previous methodological consideration of the value of consensus approaches to the illumination of nursing practice. In this case the expert consensus conference intended to overcome the paucity of published work specifically detailing the nursing role within CDM. The aims of the conference were to

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identify the range of CDM models used nationally and explore the characteristics of an enabling context for CDM, and sought to capture the dynamic, rapidly changing nature of the nursing role on the ground within CDM.

2.4.3 Identification of Participants

Expert nurses working within the field of CDM were identified via a systematic search of UK practice focused journals and websites (2.3.5).

2.4.4 Conference Methodology

Pre Planning: The planning committee was drawn from the research team, stakeholder group members (including service users) and additional recognised experts in the field of CDM. A tightly specified brief and format derived from phase one scoping exercise (appendix 2), was sent out to presenting organisations identified in phase one, who were invited to participate. The conference consisted of three working groups to focus attention on all the key aspects of model development in CDM namely; origins, process and outcomes, as specified in the SDO brief. Each working group had a link lead from the research team and facilitated a written report to be presented for the criteria identification workshop.

Role of Participants: Practitioner participants prepared a presentation on the origins, process and outcomes of their role. These were delivered in one of six simultaneous workshops, consisting of 7 – 9 participants who included non-presenting discussants drawn from user representatives and service providers.

Data Recording and Analysis: The workshops were facilitated by a chairperson and detailed notes of the discussion were taken by an additional facilitator. These were analysed thematically and support materials for a criteria identification workshop were developed. Meetings with facilitators were within five days of the conference to identify emerging themes. Each working group developed material for the consensus follow-up workshop held 8 weeks after the conference to refine the sampling frame for the case studies. A report on the thematic analysis was sent to all participants for feedback.

2.4.5 Consensus Follow-up Workshop

The post-conference workshop was held at City University, London on 8 November 2006.

Selection for attendance was based on the following criteria; completion of a data form distributed at the consensus conference that indicated a continued interest in the workshop, type of CDM model, availability of and access to data within the working environment, geographical spread and willingness from nursing management to support the participant. It was

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important to this project to include models that involve children and young people.

Following discussions, participants at the workshop were asked to complete a data form (appendix 3) that enabled the research team to reach a decision based on consensus about nursing models of CDM raised at the conference and the workshop.

2.4.6 International Panel Consultation

As part of phase 2 an on-line discussion on nursing models of CDM was set up with international experts in the field. Six experts from Canada, Australia, Iceland and Spain contributed to an on-line discussion on a dedicated website. The discussion room opened on 1st February 2007 and continued until the 2nd week of April 2007. Trigger questions (see 4.4) were offered to participants as were key documents related to the project.

2.5 Phase 3: Multiple case study evaluation

The literature suggested that there is a need to systematically evaluate the origins, processes and outcomes of models of CDM and in particular to identify the nursing, midwifery and health visiting contribution to such models. Given the complexity and multi-faceted nature of the research objectives(s) and multivariate nature of the environment in which CDM takes place, a design that most adequately addressed the research objectives in phase three was the multiple case study evaluation (Keen and Packwood, 1995; Yin, 2003a; Yin, 2003b). A case study enquiry *'copes with the technically distinctive situation in which there will be many more variables of interest than data points and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis' (Yin,* 2003b p13).

The design allows for the identification of complex contextual conditions, enabling the exploration of micro as well as macro variables and how this impacts on practice and service delivery outcomes. This research design was in keeping with the over-arching whole systems approach where the need to understand and explain the dynamic impacts of the components of the whole system on the patient and carer experience required multi-level analysis.

In this study case studies comprised typical examples of CDM models identified through the processes outlined in phases one and two. In particular, the consensus conference in phase two was key in the identification of case studies. Following the consensus conference, seven case studies were identified that included models encompassed in the long-term conditions model (Department of Health, 2005a) (see 1.3). The case studies crossed primary, secondary and intermediate care sectors.

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2.5.1 Unit of analysis

Within the case study approach, each CDM case was treated as a unit of analysis (Yin, 2003b). Thus, data collected and analysed were repeated across cases, ensuring the evaluation of the CDM model. However, to provide the comparative data, it was necessary to ensure that the theoretical and thematic linkages between each case were drawn out. For example, it may have been the facilitation style that determines successful outcomes, rather than any particular selected model or the managerial context of the case may facilitate a particular approach to CDM.

2.5.2 Explanatory model

The focus of the research demanded more than a simple descriptive approach. There was a need to build explanations as to why the CDM model may have more impact in one case than another or for a certain cohort of patients, e.g. young people with asthma. Thus, within the typology of case study approaches proposed within the literature (Marinetto, 1999; Yin, 2003a; Yin, 2003b), the most appropriate method is argued to be the 'explanatory case study' (Yin, 2003b). The goal of explanation building is 'to analyse the case study data by building an explanation about the case'. Explanation is guided through key theoretical propositions and demonstrated through narrative. The use of an iterative data process ensures that a final explanatory model can be arrived at (Marinetto, 1999).

2.5.3 Selection of case studies

As described above, the identification of the case studies was arrived at through the process of consensus and identification from the literature of the key principles of CDM and the sampling of such cases from all levels of the long-term conditions model (Department of Health, 2005a) drawing on the consensus conference and the stakeholder workshop to inform the final selection. In using this approach we were aware that there would be an element of selection bias as it was likely that those organisations taking part in the conference would be keen to be part of the study. However, it was important that the case studies were purposively sampled as it was axiomatic that they should be largely nurse-led and demonstrative of different types of models. However, a risk stratification model proved less useful as a guide to case study selection as it became obvious from the mapping of the literature, the consensus conference and website mapping that there were very few, if any, models of CDM that were truly preventative at the primary level. We found no examples of CDM that were led by health visitors or midwives, although there were sporadic references to their health promotion role these could not be described as CDM. Therefore, the case study models that were finally selected represented the severe end of chronicity and co-morbidity, the self-caring/management level of CDM and the secondary prevention level. The case study models were all led by nurses of different types and specialty

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and represented primary, secondary and intermediate care and users of all ages. These were:

Case management Model (2 sites)– This model was initially explored from two perspectives, the case management of complex conditions among older people by community matrons in primary care and the case management of young people in transition with complex conditions across health and social care. The case study concerning young people in transition was unfortunately withdrawn from the study due to poor recruitment of young people and health professionals. In the adult case management site there were also problems with recruitment of staff due to concurrent major organisational changes, however a sample of service users were recruited. Therefore, late on in the project, a third adult site agreed to participate in the study and data were collected from community nurses, managers and other nurses involved in the case management of older people with LTCs. Unfortunately, although information packs about the study were distributed by community matrons to patients on their caseload, we were unable to recruit any service users in this site.

Primary Care Model (2 sites) – The primary care model was represented by two sites. Both sites relied on the practice nurse/nurse practitioner role in collaboration with the General Practitioner in managing LTCs in primary care settings. The first was based in Wales and was centred around the management of diabetes across the practice population by the practice nurse. The second was in England and involved practice nurses working across a range of long-term conditions in primary care.

Nurse Specialist Model (2 sites) – The nurse specialist was represented both by the clinical nurse specialist and the consultant nurse roles. Both of these models were based in England in secondary care with out-reach and hospital based clinics. The clinical nurse specialist worked highly autonomously in collaboration with a consultant neurologist to support people with epilepsy. The consultant nurse was based in a diabetes unit with a team of nurses and doctors.

Public Health Model (1 site) – The public health model was represented by a school health advisor role based in a Primary Care Trust where the school health advisor had led on a Trust-wide strategy for management of childhood asthma in schools. The case study focussed on young people aged 7 to 16.

The context and population detail of each case study is described later in the report as part of the findings section 5.

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2.5.4 Data collection

Explanation building depends on data and, the case study method allows for a wide range of data to be collected and analysed. The focus here was to explore, explain and assess the origins, processes and outcomes of CDM models and the nursing contribution to these. Data were collected using the following approaches:

***Semi-structured interviews*:** A primarily qualitative approach is necessary to understand and explain the patient experiences of the CDM model. Thus, the main form of data collection was through a semi-structured interview. Five schedules were designed in collaboration with service users and piloted with age specific reference groups. Four were directed towards eliciting adult patient (appendix 4), carer (appendix 5), parent (appendix 6) and younger person (appendix 7) views and experiences, whilst the fifth was directed towards those professionals responsible for any programme (appendix 8). The themes within the interviews built upon the theoretical propositions and analysis from phases 1 and 2. Patients and service users with a range of profiles were purposively selected from each model of service for in-depth analysis. We included interviews with service users, family carers and professional carers including GPs, nurses, and hospital consultants. We included participants from across all age groups, ethnic and social groupings. We used constant comparative analysis to identify characteristics of nursing (caring) practice associated with management of chronic diseases that enabled explanation building of the patient/service user experience and the nursing contribution.

***Focus groups*:** A review of the literature reveals that focus groups represent an established method that has been extensively and successfully employed in research with young people. In addition it has been found to be an appropriate, safe and ethically sound method, for children aged 7-11 (Morgan *et al,* 2002). In the health field, the method has been very widely used with children, in order to explore their views on a wide range of health related-topics, including social pressures and health (Dixey *et al,* 2001b), eating disorders (Dixey *et al,* 2001a), and childhood conditions (Ronen *et al,* 2001). Moreover, focus groups with children and young people have also been used to conduct research on very sensitive topics, with vulnerable groups of children. This research has covered topics with children, aged between 8 and 14, such as child abuse (Charlesworth & Rodwell, 1997). A focus group schedule was specifically designed to elicit adolescents' (11-16 years) and children's (7-10 years) (appendix 9) views and experiences of the nurse-led asthma strategy. Two focus groups were conducted at mutually agreeable times for the children or younger person's school.

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***Survey using questionnaires*:** To measure the impact of the assessed models represented by the case studies, on outcomes for service users, a selection of generic outcome measures were collected through patient questionnaires. This part of the study was undertaken in collaboration with the CHKS Health Economics Unit, Cardiff Research Consortium Ltd. and used the Health Outcomes Data Repository (HODaR) (http://www.cardiff-research-consortium.co.uk/) that holds data describing the care and outcomes (including EuroQol and SF12) of more than 60,000 patients. The outcomes measured were patient centred to include:

CDM 6 item self-efficacy questionnaire (Stanford University, 2005),

EuroQol (EQ-5D), SF12

Health and Social Service Utilisation based on HODaR database

Data were collected via postal survey (appendix 10) to service users and benchmarked against the indicators available in the HODaR data to provide a profile of outcomes for each model of service. The young person's survey data (appendix 11) were collected and analysed separately as the HoDAR database does not include children. These data were benchmarked against the Health Behaviour of School Aged Children Survey (World Health Organisation, 2008)

Documentary analysis: Operational and strategic plans were examined as well as annual reports of Trusts to identify organisational context and the integration of the service in relation to organisational objectives and commissioning

2.5.5 Samples

The samples for each case depended upon the type of model and the patient population. It was therefore the models that drove the sampling decisions, not long term conditions per se. Community matrons tend on average to manage caseloads of about 50 patients whereas in the public health model the school health advisors were managing the whole school age population with asthma within that PCT.

Sample size estimation for the surveys

Depending on the size and structure of the case load we therefore either undertook a census of all patients or selected a random sample. It was not possible to determine the size of the sample statistically in order to undertake a powered study as the parameters of the study population were not known. However in looking at HbA1c, for example, the mean and standard deviations reported in the Health Survey for England was 7.64 and 1.45 respectively. If observing a 0.4% absolute change in HbA1c between centres, for example, the study would have 92% power to detect a difference. The analysis of quality of life data sought to characterise changes within cases and were used as a potential confounding variable in analysing clinical variables. Also, as would be anticipated, the case study

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populations were highly heterogeneous, and often included more than one diagnostic group, therefore, population norms and standard deviations for single diagnostic groups were not helpful in determining sample size. Eventually, the sample size from each case was determined with advice from the Cardiff Research Consortium who manages HODaR at 300 per case site for the survey element of the study, based on characteristics of the study population, the availability of applicable prior information on the population parameters being measured and the fit with data held in HODaR. Patient outcome data were collected on patients at between 3 to 6 months after entry into the study, based on the service as it was being delivered. We aimed to benchmark these patient outcomes against national data available from HODaR to provide a description of the distribution of key outcome variables for the case study population when compared to population norms. We appreciate this did not provide statistically significant outcomes, but provided evidence of the distribution of these variables for the populations being studied which can be used to power future studies into CDM. In the event, the samples we obtained were much lower than the anticipated 300 as will be discussed later. In some cases, we elected to be more purposeful towards the population under consideration. For example, in NS1 we wanted to ensure that a model that had arisen through the process of mapping and the consensus conference was included. This meant that the population under study were part of a diabetes education model led by a specialist nursing team and that the final sample were a subset of this population that might in some ways be different from the general population of people with diabetes in the community. However, the latter were covered by the primary care model (PCN1). We felt this decision was justified as it was the models that were of primary interest, not the medical condition itself.

For the young person's survey and primary school sample a purposive sample of seven secondary schools and three primary schools was undertaken to reflect a range of schools in terms of attainment, socioeconomic status of catchment area etc. However, the sample then depended on permission for access and whether the asthma register was up to date. (There were 80 primary and 21 secondary schools in the borough). From the seven secondary schools a census sample was conducted and all 328 young people on the asthma register were sent the survey (Appendix 11). The pack included a letter inviting their parent to be interviewed. Letters were also sent to the parents of all the children on the asthma register in the three primary schools inviting them to be interviewed and asking their child if they would like to take part in a focus group. Both surveys and letters were sent out by the local collaborator and there was not enough administrative capacity to send out reminders.

Sample size estimation for the interviews/focus groups

The samples for the qualitative elements of the cases were arrived at through a process of theoretical sampling. This approach is drawn from

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the field of grounded theory (Strauss and Corbin, 1990), whereby interviewees responses are analysed as the study progresses and as new themes or categories emerge these are threaded into the next interview in order to build the theoretical understanding that is emerging. The aim is to ensure that there is sufficient variability in the data to contribute to theoretical generalisation across cases rather than statistical distribution and generalisation. . There is therefore no fixed sample size and this varied in this study across the cases from between 7 and 28 interviews. An overview of each sample per site can be found in table 1.

Table 1– overview of respondent numbers per site

Site	Survey Responses	Surveys Dispatched	Survey Response rate	Number Interviewed				
				Patients/younger people	Carers/ parents	Health Professionals		
						Nurses	Doctors	Others
PCN 1	64 312		21%	17	2	3	1	4
PCN 2	75 300		25%	13	2	5	1	2
NS1 101		395	26%	17	4	4	2	1
NS2 73		300	24%	11	3	4	1	5
CM1 34		-	-	6	2	0	0	0
CM2 N/A		N/A	N/A	0	0	5	0	2
PH	75	328	23%	9 (6 in focus groups 3 interviewed)	4	11		

As can be seen, whilst the response rate for the survey was reasonably consistent (although low 21-26%) between cases, there was considerable variability in qualitative samples. In CM2 no interview data were collected as the patients and carers in this initial case study were just too frail to take part in the interviews. In each of the other case studies, the number of participants recruited was justified by the degree of saturation that was being reached through the interview process. This was determined by the lead researcher for each case study with associated inter-rater validation of the themes and categories that were identified from the data.

2.5.6 Quantitative analysis

Analysis of data was undertaken both within each case study site and between the case study sites so as to provide some explanation of the impact of the intervention across differing contexts and to account for any confounding variables that are outside of the control of any organisational research (e.g. media led initiatives). The questionnaire data were analysed quantitatively by health economists at CRC Ltd. and compared with national data for the relevant population. HODaR consists of a unique database comprising both inpatient and outpatient Quality of Life (QoL) cost and clinical information (such as biochemistry and haematology),

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drug and resource use across all disease groups. In July 2005 it contained data from more than 50,000 responses and is currently growing at more than 2,000 subjects per month. Recently it has expanded to recruit patients from primary care (Currie et al, 2005).

HODaR supplements routine clinically coded data with questionnaire data covering socio-demographic characteristics, QoL (SF12, EuroQol), and service utilisation. We supplemented this questionnaire with the generic self-efficacy scale (Stanford University, 2005). The questionnaires are usually sent out by CRC Ltd. to all patients over the age of 18, (excluding those admitted with a primary diagnosis for a psychological illness and/or with a recorded learning disability or who are known to have died), who are discharged from Cardiff and Vale NHS Trust. Outpatients are surveyed on a rotating basis. Patients who return the questionnaires and the signed informed consent form are included in the HODaR database. Questionnaires are distributed and analysed by the Trust as part of their quality assurance programme. Only coded anonymised questionnaires and matched coded and anonymised clinical data are passed onto HODaR. The key feature of HODaR is the linking of routine clinically coded health service data to QoL and utility data matched using a unique coded identifier. The survey is planned to be indefinite in order to collate detailed longitudinal data. HODaR hold longitudinal data on 898 patients who have returned more than one set of survey data.

The decision to include HODaR in our study was based on a number of considerations:

Unique database - it is a unique database focusing on key areas of interest in CDM including quality of life and service utilisation both of which feature heavily in all the policy literature on the management of long-term conditions. The specific nursing contribution to these dual outcomes has been difficult to determine using quantitative methods. Benchmarking these outcomes for nurse run services against population parameters of a matched sample of patients on the HODaR database, would, we anticipated, produce evidence on the contribution made by the sampled nursing services to these outcomes.

Whole systems methodology - the data collected by HODaR reflect the same components of data identified in our previous research using whole systems methods (Procter *et al*, 2000). While we recognise that these data elements are fairly standard, the analysis of these elements using a whole systems methodology recognises the proactive role of patients and carers in responding to their situation and in determining access to and utilisation of services. These elements were therefore analysed to identify drivers to effective and ineffective care within the local health and social care economy. The contribution of nursing to CDM and the patient experience was analysed in this context.

The need to develop research methods that can measure nursing outcomes has long been recognised. However, very little progress has actually been made. Nursing evidence is often viewed as 'soft' and

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consequently frequently excluded from systematic reviews. Not only does this hamper our understanding of where nursing resources can be most effectively utilised, it also hampers our ability to understand how to re-design services to meet future health care needs. HODaR data were included in this study to address one arm of the evidence debate namely the need for hard measures of outcomes of impact and effectiveness. Findings using HODaR data were allied to theoretical debates about the patient experience and service delivery drawing on the strengths of qualitative methods to develop an enhanced level of analysis which combines both types of data.

Track record - HODaR has been successfully used in a range of published studies (Davis *et al*, 2005; Lee *et al*, 2005a; Lee *et al*, 2005b) designed to identify the key variables which impact on quality of life outcomes for patients in different specific disease categories. CRC Ltd. has undertaken commercial research for a wide range of pharmaceutical companies including: Allergan AstraZeneca, Aventis, Boehringer Ingelheim, Bristol-Myers Squibb, GlaxoSmithKline, Johnson and Johnson, Lilly and Company, Novo Nordisk, Pfizer, Pharmacia Upjohn, Roche, Sanofi-Synthelabo, Takeda, and Wyeth.

However, we recognise some limitations of using HODaR. HODaR data are based primarily on a hospital and outpatient population and so is not representative of the total population. Their respondents differ to a small extent from our target population because of non-response, the exclusion of deaths and the limited, although growing, range of primary care data. General analysis of HODaR data indicates large standard errors and skewness in the analysis of EuroQol data (Currie et al 2005). This highlights the importance of ensuring a good match between our patient population and the comparative population derived from the HODaR dataset. However, matching was limited to known variables, we had no way of knowing from the HODaR data if the matched sample had recently been in receipt of services similar to our case study models. Finally, HODaR data are gained from Cardiff and The Vale of Glamorgan. However, a comparison of the HODaR population with the population of England and Wales based on the 2001 census using: demographic variables; percent reporting limiting long-term illness; percent of economically active unemployed; Townsend index of material deprivation; inpatient hospitalisation per 1000 of population; standard mortality ratios and life expectancy at birth, reveals a broadly similar distribution (Currie *et al*, 2005). However, these global figures mask important differences at a local level, for instance, ethnic minority populations in England are concentrated in certain urban areas and in particular in London, which might have a very different population profile to the rest of the UK. Parts of London also have a growing young population, which contrasts markedly with other parts of England and Wales, although this is mirrored in Cardiff. These demographic variables were taken into consideration in selecting the case studies to ensure the validity of the final analysis.

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As with all data sources, the weaknesses of HODaR had to be considered in the light of specific study objectives. While HODaR clearly does have some limitations, it does provide a unique opportunity to progress understanding of nursing outcomes for a complex group of patients with multiple health care needs. The limitations of the HODaR database needed to be considered in selecting case studies and in the subsequent analysis of data to ensure internal validity. In undertaking this analysis it was important to check the external validity of the comparisons being made, where necessary using census data on the local population from whom the patient sample for the case studies was derived. In the event, we were not able to effectively benchmark each of our case study models with HODaR because:

1. HODaR do not hold data on children and young people (thus these data were benchmarked separately against the England-wide Health Behaviour of School Aged Children survey).

2. Limited response rate from our sample led to very small cell sizes for each model

3.HODaR do not collect data on self-efficacy

Therefore the benchmarking was largely conducted at the higher level of analysis against our total patient respondents (n=347).

2.5.7 Qualitative analysis

The interview and focus group data were transcribed verbatim by a professional transcriber and coded using the qualitative research package; NVIVO 7 (QSR International Pty Ltd, 2006).Qualitative data analysis drawing on thematic content analysis and grounded theory approach (Seale, 2004) enabled the key attributes and features of the nursing and patient experience of CDM to be distilled from the data. The four principles of whole system methodology described by Kendrick and Conway (2003) and outlined above were used to guide data analysis. Both similarities and differences between case studies were of importance in building the explanatory model of what works under different conditions and why. Transcripts were open coded by members of the research team. Regular team meetings occurred to enable a common understanding of the open codes and development of tree nodes. Researchers outside of the immediate team cross checked coded transcripts and coded transcripts independently to aid inter-rater reliability. A sub-group of lay service user representatives from the project advisory group coded a sample of transcripts to enable vicarious respondent validation. Any variation in interpretation was discussed with the source respondent. Development of themes and categories was facilitated by a series of summative analysis meetings of the research team.

Through an iterative process of theory building from the data sets the explanatory model is thought to be of value to other areas of the NHS

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when putting together similar models to meet the National Service Framework requirements for long-term conditions. Thus, we would argue, not for generalisability of the findings on a statistical scale, but for transferability between cases that will allow for local and national adaptation.

2.6 Project steering group & public involvement

Members of the project steering group are listed at the front of this report. The group played a vital role in grounding the project to reflect a range of constituents, for example; service users, health professionals and the wider community. They also provided challenge and acted as a sounding board, providing critical commentary as the project developed.

Public involvement underpinned the development, process and outcome of the project. Initial discussions were held with diabetes and arthritis service user representatives to ensure we had captured their viewpoint during the proposal development; they also reviewed lay summaries and participant information sheets. A member of the Public Involvement in Research Group (PIRG) within CRIPACC, University of Hertfordshire joined the project steering group as did a rheumatoid arthritis service user recruited from outside of the PIRG. Service users representing diabetes, osteoporosis, arthritis and neurological conditions were invited to the consensus conference and were actively involved in small workshop discussions. A sub-group of younger people were involved in the development of participant information sheets for children and adolescents. Service users on the steering group gave advice on recruitment and interview schedules during the data collection phase. During the analysis process they independently reviewed a sample of transcripts from each case study site and joined research team discussions on the emerging themes. They reviewed sections of the final report and were actively involved in the dissemination process.

2.8 Ethics and research governance

NHS research ethics committee approval was gained prior to commencement of data collection (appendix 12). This was applicable for all seven case study sites which were all deemed to be exempt from a site specific assessment. Gaining research governance approval was more complex as three of the case study sites requested changes to the recruitment of participants, and concurrent NHS reorganisations had an impact on the speed of research governance processes resulting in a six month delay to the original time frame. A substantial amendment was granted by the ethics committee (appendix 13) to allow recruitment of participants to be carried out by the local collaborator rather than the research team; the recruitment process in the adult sites is illustrated in appendix 14. A similar process occurred in the younger person case study site (appendix 15). Primary school children did not take part in the survey and so information about the children taking part in a focus group and

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inviting parents to be interviewed was distributed to parents of these children via the school. Parents who replied via a pre-paid response form were then contacted by phone to arrange the date, time and venue of the focus group or interview. All parents were interviewed via the telephone with consent forms posted back in a pre-paid envelope. Staff were recruited in a similar way to the adult sites although some of the interviews were carried out face to face rather than by telephone.

It was originally intended that qualitative data would be collected via focus groups with young people and children. However, it became apparent that some children and young people were unable to attend a focus group because of their social circumstances. An amendment was approved by the research ethics committee (appendix 16) for the use of a one to one semi-structured interview for adolescents who could not attend a focus group.

As fieldwork continued it emerged in the younger person's site that the nurses had a significant public health role within CDM. Nurses were central to the development of a school asthma policy which covered the majority of schools in this case study site. Although children and adolescents may not have had direct contact with the nurse, nurses within the site had had a considerable influence on the school asthma strategy and hence the CDM for this population. We wished to investigate this public health aspect to the role by extending the focus group sample to children covered by the school asthma service rather than being explicitly on a nurses' caseload, and extending the survey sample to the young people covered by the school asthma service. Because the children and younger people covered by the school asthma service may not have had direct contact with a nurse, new and revised versions of the information sheets and invitation letter were required and approved by the research ethics committee (appendix 17). Full written consent (adolescents, parents of primary school children, and parents participating in an interview) and an assent form completed by primary school children was taken prior to the commencement of focus groups or interviews. All participants were debriefed at the end of the interview or focus group and thanked for their input; children and adolescents were give a ten pound token as an appreciation of their time.

Interviews in child and adult sites and focus groups in the child site were digitally recorded and anonymised during the process of transcription. Digital recordings were deleted at the end of the study. All data were handled as per good ethical practice using anonymised codes at all times. Data were stored in accordance with the requirements of the Data Protection Act. Electronic files were securely held on password protected computers and any hard copies were stored in locked filing cabinets within locked offices. Data were only accessible to the research team. All identifying information was removed from the adult survey databases when transferred to HODaR. The transfer was done in person via a password protected USB.

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We described the problems of recruitment in two of the sites in 2.5.3. Due to research governance processes the research team were unable to recruit directly or obtain a demographic profile of non-respondents. At the time of data collection the UK Clinical Research Network Coordinating Centre was just being developed and processes for local networks to facilitate recruitment for adopted studies was only beginning to emerge. It is possible that some of the problems we encountered would now be ameliorated.

2.9 Summary

Drawing on whole systems methodology which focuses enquiry on the causal, data, organisational and patient experience of the whole system, the research was conducted in three phases.

A nationwide internet based scoping and systematic mapping of the literature aimed to identify examples and map models of CDM involving nurses. This first phase allowed identification of participants for a national stakeholder consensus conference in phase two. The conference sought to capture the dynamic, rapidly changing nature of the nurse's role within CDM. The conference was followed up by a workshop which formed the basis of a sampling frame for case study selection in phase three. Concurrent to the conference and workshop an international panel of nurse experts in CDM discussed on-line the international context of the nursing contribution to CDM.

Seven case study sites providing examples of four different models of CDM across the lifespan were evaluated in phase three. These included the community matron, condition specific nurse specialist, primary care and public health models. Data were collected through semi-structured interviews, focus groups, survey using questionnaires and documentary analysis. We interviewed or conducted focus groups with 73 service users, 17 carers, 32 nurses, 7 doctors and 14 other health professionals and managers. We dispatched over 1600 surveys but only had a response rate averaging 24 percent.

Survey data were analysed quantitatively and compared to the HODaR database of a relevant adult population, or in the case of younger people against the Health Behaviour of School Aged Children Survey (World Health Organisation, 2008). Qualitative data analysis drew on thematic content analysis and a grounded theory approach.

Throughout all stages of the research service user representatives were involved in the design, management and dissemination of the project. NHS ethics and governance approval was obtained for the study.

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3 Mapping of the literature

The aims and inclusion criteria for the mapping of the literature are described in 2.3 and 2.3.1.

3.1 Types of studies

Overall 203 papers reporting 183 studies met our inclusion criteria. Of those 156 (76.8%) were classified as outcome studies (e.g. RCTs and other quantitative studies), 27 (13.3%) views or experiences studies (e.g. qualitative studies) and 20 (9.9%) as descriptive studies (e.g. surveys). The majority of included studies were conducted in the UK, North America and Europe. A full list of included studies can be seen in appendix 18.

3.2 Types of participants

Studies were further categorised by the type of disease or illness. There was a wide variation in the type of condition and the severity of disease although cardiovascular disease and diabetes were the most common conditions addressed by the papers. A breakdown of the types of studies and disease categories can be seen in table 2. Although the age range of participants varied a significant proportion of the studies involved older people, many of whom had significant co-morbidities.

3.3 Type of intervention / model

We classified outcome studies according to the Kaiser Permanente Triangle (health promotion, self care support/management, high risk, or highly complex needs) (Department of Health, 2004a). The majority of included studies were clustered around the two middle sections of the triangle – self care support and management (n= 157), and high risk condition specific (n= 195); rather than highly complex needs (n=13) or health promotion (n=46). However, in reality, we found that the model was not particularly useful as, in the majority of cases, there was overlap between the different categories and many nursing roles or interventions did not fit easily into only one section of the triangle. In addition, as many studies did not give detailed descriptions of what the intervention entailed, it was not always easy to categorise the study.

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Table 2. Types of studies and disease categories.

Disease category	Number of papers	Outcome studies	Surveys	Views and experience studies	Number of studies
Asthma 25		22	2	1	23
Anticoagulation 4		4	0	0	3
Bowel disease	3	3	0	0	3
Cardiovascular 39		29	3	7	32
COPD/respiratory 13		10	2	1	13
Dermatology 3		3	0	0	3
Diabetes 45		32	8	5	43
Epilepsy 10		6	1	3	8
Health promotion	7	7	0	0	7
HIV 2		0	2	0	2
Hypertension 7		6	1	0	7
MS 2		2	0	0	2
Not condition specific	18	10	1	7	16
Parkinson's disease	5	5	0	0	3
Rheumatology 10		10	0	0	8
Stroke 7		5	0	2	7
Other (n = 1 of chronic dizziness, chronic pain, leg ulcers)	3 2			1	3
Total number of studies	**203**	**156**	**20**	**27**	**183**

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The models that were best described and evaluated in the literature were case management and disease management. Although we categorised these separately there was often considerable overlap in the nurse's role. However, case management tended to involve a greater responsibility for co-ordinating care. In addition, other studies, such as those looking at hospital at home, often included an element of case management. Although not classified as a model of care one type of nurse role that was a feature of many studies was nurse run clinics. This often involved nurses undertaking roles and responsibilities that might previously have been done by doctors. The promotion of self-management was a fundamental part of many of the interventions. For example, case management, disease management and educational interventions often included some form of education aimed at improving self care. However, it was often not clear if this was delivered in a didactic fashion or using techniques specifically designed to promote self-management skills.

A number of commonalities around the type of intervention or model emerged from the literature and from these we developed categories which were used to structure the evaluation. These were:

- Case management (defined as a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes – Case Management Society of America).

- Disease management (these were generally multifaceted interventions that aimed to help manage a chronic condition. Often included education, promotion of self-management, assessment and monitoring).

- Clinics run by nurses (although the patient may also see a doctor this term is used to describe clinics where a nurse sees patients independently, it often involves the substitution of care by a doctor for care by a nurse).

- Education or health promotion. In most studies nurses were involved in some form of education or advice giving and this was often a major component of their role. However, we only used this category for studies where the main focus of the intervention was on education, counselling or health promotion. For example, behavioural interventions where the focus was on increasing knowledge and/or developing self management skills, or health promotion interventions such as those aimed at smoking cessation.

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- Services delivered in the home (e.g. hospital at home/home visits). This often involved the transfer of care from secondary to primary care.
- Discharge planning.
- Technology based care (e.g. remote video links).
- Disease specific specialist nurse services.

There was, however, considerable overlap between the categories. For example nurse run clinics often included elements of other categories such as education, health promotion, and could potentially be classified as disease management.

3.4 Findings

Study quality

The majority of the systematic reviews were of reasonable quality. Based on the NICE criteria eight were graded as (++), three as (+) and four as (-). The overall quality of the RCTs was, however, poor. For example, only 23 of 88 RCTs were judged to have adequate allocation concealment. Full results of the quality assessment can be seen in appendix 19.

3.4.1 The nature of the nurses' role

Nurses were involved in a variety of interventions including running clinics, delivering services in the home, education and health promotion, case and disease management and discharge planning. Nurses had a variety of titles including specialist nurse (n=70), nurse practitioner (n=6), advanced practice nurse (n=5), practice or primary care nurse (n=25), district nurse or community nurse (n=10) and nurse case manager (n=15). Less frequently used titles included research nurse, school nurse, nurse educator, asthma nurse or stroke nurse. In some studies titles were not given. We found no studies that involved midwives or health visitors in CDM and although a number of studies looked at case management we found only one study that looked specifically at the role of the community matron in the UK (Drennan 2005). There appeared to be considerable overlap between the different titles, a lack of clarity about role definition and some confusion about the specifics of each role and the qualifications and skills needed. For example, although 'specialist nurse' was the most commonly used title it was often not clear exactly what the role entailed and the same job and title appeared to be held by nurses doing different tasks, with different responsibilities and differing levels of skills and training. Success in the role appeared to be more dependent on the

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individual qualities of the nurses involved than in structured posts or training.

Nurses were often undertaking tasks that had previously been done by doctors such as running clinics. We found 48 studies that appeared to involve the substitution of nurses for other health care professionals, for example nurses undertaking tasks previously done by doctors. However in many cases the substitution was only partial with the nursing service being additional to the services of a doctor rather than a straight replacement. This may be because many nurses were not able to prescribe medication, order investigations or make referrals. Indeed, only 27 studies specified that nurses could alter or prescribe medication and in nearly half this was limited to titration or modification of drugs previously prescribed by a doctor. As previously pointed out, in a review evaluating substitution of doctors by nurses in primary care, (Laurant, 2004) although doctor-nurse substitution has the potential to reduce doctors' workload it does not always do so. This may be either because nurses are being used to meet previously unmet patient need, by providing a new service, or because nurses may generate demand for care where previously there was none.

Several studies described UK based interventions that were intended to improve the primary/secondary care interface. In general these interventions appeared to improve communication between health care professionals although the effect on clinical outcomes was less clear. A number of studies involved the shift of health care services from secondary to primary care with primary care nurses taking on chronic disease roles that had previously been the remit of secondary care.

3.4.2 Training and qualifications

In 113 studies the experience or qualifications of the nurses involved were not clear. In 52 studies it was reported that the nurses had some form of specialist training. This included recognised certificates or training courses; 'on the job' training; or training designed specifically for the study. The amount of 'on the job' training or training to deliver a specific intervention appeared to vary greatly ranging from months to a few hours only. However, in many cases the intensity and duration of 'on the job' training was not reported. In 57 studies it was specified that the nurses had relevant experience in the speciality or intervention concerned; in some cases over many years. What was apparent was that although many nurses had extensive training or experience this was not always the case and that there was often no formal or established training pathway. Indeed it appears that UK educational standards are less clearly defined than in the US and qualification for many nursing roles tend to depend largely on a nurse's level of clinical experience.

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3.4.3 Effectiveness of nursing interventions

In this section we examine the effectiveness of nursing interventions for people with chronic disease. Although this is based on the results of a large number of studies, including 16 systematic reviews, 88 RCTs and 9 controlled studies, the nature of the mapping means that we may not have included all relevant studies. Therefore, the observations about effectiveness should be interpreted with some caution. It should also be noted that whilst some interventions aimed to improve outcomes in the intervention group others were concerned with assessing whether the intervention was as safe and effective as existing services. In the latter studies equivalence may be regarded as a desirable outcome. In this section we report key results by model/intervention type and by disease category. A more detailed presentation of results can be seen in the evidence tables in appendix 20.

CASE MANAGEMENT

Sixteen studies (two reviews, 11 RCTs and three controlled studies) evaluated case management (CM) for people with a LTC.

Not condition specific

Two RCTs and two controlled studies evaluated CM in general or mixed populations. Two were conducted in the USA, one in Canada and one in the UK. The UK controlled study (Gravelle 2006) evaluated CM for frail elderly people. CM, based on the Evercare model, was delivered to 64 primary care practices by advanced practice nurses and was compared to treatment as usual (TAU). Qualitative evidence showed that CM introduced an additional range of services in primary care such as regular monitoring, psychosocial support and referral. However, there were no statistically significant effects on the primary outcomes emergency admissions and mortality. The Canadian RCT (n=427) also evaluated nurse CM for frail older people (Gagnon 1999). They found no significant differences in QoL, patient satisfaction, activities of daily living, hospital admissions or length of hospital stay. In addition, the intervention group had significantly more visits to the emergency department (ED). The other US RCT (n=212) evaluated CM with the use of home visits and remote video technology (Johnston 2000) for patients with newly diagnosed chronic disease. There were no significant differences in compliance, knowledge, patient satisfaction or service use but there was a cost saving associated with the intervention. The only study to find significant benefits was a small US study (n=54) looking at the effect of community based CM for older people with chronic disease (Boyd 1996). The intervention group had significantly reduced service use and was associated with cost savings compared to the control.

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Asthma

A small US study (n=57) (Greineder 1998) compared an asthma outreach and CM programme for children and their parents with a single asthma education session. They found a reduction in ED visits and hospitalisations in the intervention group compared to control.

Cardiovascular

Two US based RCTs with a total of 690 participants compared nurse CM to TAU. Results were mixed. In one (Allen 2002) they found significantly better lipid control, dietary consumption and physical activity levels in the nurse CM group. In the other (DeBusk 2004) they found no significant differences between groups in service use, use of cardiac medication or mortality.

Chronic Obstructive Pulmonary Disease (COPD)

One systematic review, including nine RCTs and 662 participants, (Taylor 2005) evaluated nurse run management of COPD. Most of the included studies evaluated some form of CM with the promotion of self-management as key. They found insufficient evidence to support widespread implementation although there was not enough data to exclude clinically relevant benefit or harm.

Diabetes

One systematic review, five RCTs, and one controlled study evaluated nurse CM. The review (Loveman 2003) assessed the effects of diabetes specialist nurses and nurse CM on the metabolic control of diabetic patients. They included six studies, five of which were RCTs, with a total of 1382 participants. The main outcome was glycated haemoglobin (HbA1c). Although some of the studies showed an overall improvement in the intervention group compared to control there was no significant difference in five out of six of the studies at 12 months follow up. There were also no statistically significant differences in ED visits, hospitalisations or QoL. There was no information found on BMI, mortality, long-term diabetic complications, adverse effects or costs. The authors conclude that the current research does not provide evidence that diabetes specialist nurses or case managers are effective in the long term.

Nurse CM for patients with diabetes was evaluated in five RCTs and one controlled study. The studies, all from the US, had a total of 1575 participants. The main outcomes measured were HbA1c, lipid levels and blood pressure. One small study (n=89) of nurse telephone CM and education for children with type 1 diabetes found no significant difference

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in glycaemic control or diabetes knowledge but a significant improvement in adherence compared to TAU control (Howe 2005). In the other five studies they evaluated nurse CM in adults. Results from the studies were mixed. Only two studies reported significant improvements in glycaemic control. One, an RCT (n=269), (Taylor 2003) evaluated integrated nurse CM in a Kaiser Permanente Medical Centre compared to TAU from a primary care physician. At 12 months they found that mean changes in HbA1c and LDL were significantly greater for the intervention than the control group. There were no significant differences in any psychosocial variables or resource use. In the other, a controlled study (n=453), (Fanning 2004) they compared nurse CM, using treatment algorithms, with TAU in a family practice clinic. They found significantly better glycaemic control, fasting plasma glucose and total cholesterol in the intervention group compared to the control. There was no significant effect on blood pressure or body weight.

Two RCTs found no effect on glycaemic control but reported improvements in other outcomes such as blood pressure. One study (n=332) (Gabbay 2006) evaluated patient orientated nurse CM compared to TAU by the patient's primary care physician. They found a significant improvement in blood pressure but no effect on glycaemic control or lipid levels. The other (Gary 2003) looked at the effect of care by a nurse CM or community health worker on diabetic control in African Americans with type 2 diabetes. At two year follow up they found no significant effect on glycaemic control, dietary practices or physical activity but a significant difference in blood pressure and triglycerides when both intervention groups (nurse case manager and community health worker) combined were compared to TAU control. One study with 246 participants (Krein 2004) found no effect on any clinical outcomes when comparing nurse CM with TAU from a primary care physician for adults with poorly controlled type 2 diabetes. However, patients in the intervention group were more satisfied with their care.

Hypertension

A US RCT (Bosworth 2005) (n=588) evaluated nurse administered telephone CM which involved telephone contact every two months for two years. They found a significant increase in self confidence of hypertension management compared to the control but no effect on hypertension knowledge or self-reported medication adherence.

DISEASE MANAGEMENT

Eleven RCTs evaluated disease management (DM) programmes, the majority of studies involved patients with asthma and diabetes.

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Asthma

Five RCTs, with a total of 641 participants, evaluated some form of DM programme. These generally involved specialist nurses working in both hospital and community settings. Two studies were conducted in the UK, two in America and one in Canada. One study (Pinnock 2003) had an associated economic analysis (Pinnock 2005).

Four studies involved multifaceted programmes that included education, the promotion of self-management and follow up or outreach in the home (Castro 2003, Hughes 1991, Kelly 200, Smith 2005). Two studies included children (Hughes 1991, Kelly 2000) and two adults (Castro 2003, Smith 2005). Results from the studies were mixed. Although no studies reported adverse or worse outcomes with the nurse run interventions not all found significant results. However, all four studies were small with less than 100 participants. The other study (n=278) (Pinnock 2003) evaluated the method of delivery rather than the content. They compared telephone review with face to face consultations. They found that a greater number of patients could be reviewed by telephone and there were no significant differences in outcomes. In addition, the mean cost of telephone review was lower than a face to face interview (Pinnock 2005)

Diabetes

Four RCTs evaluated some form of disease management (DM) for patients with diabetes, two were conducted in the USA and two in the UK. In general results were mixed. The UK RCT (n=300) (Davies 2001) compared a hospital diabetes specialist nursing service with TAU and found a reduction in costs, length of stay and GP contacts and greater knowledge and satisfaction in the intervention group. However, there was no significant effect on readmissions or quality of life. Another RCT (Litaker 2003) evaluated DM by a nurse practitioner for patients with hypertension and type 2 diabetes. They found a significant difference in glycaemic control and HDL cholesterol in the intervention group compared to control but no effect on total cholesterol, blood pressure or QoL. Patients in the intervention group were, in general, more satisfied but costs were significantly higher. Two US studies evaluated automated telephone DM by a nurse (Piette 2000, Piette 2001). There was no effect on unadjusted glycaemic control in either study although both found a significant improvement in diabetic related symptoms.

Hypertension

Two RCTs evaluated interventions that we classified as DM. In one US RCT (n=150) (Rudd 2004) they evaluated the effect of a physician directed, nurse-managed home-based system for hypertension management. They found improvements in blood pressure and greater

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medication adherence in the intervention group. In the other study, a UK RCT (Schroeder 2005) (n=245) an intervention to promote medication adherence found no statistically significant effect on compliance or blood pressure. However, the authors note that compliance in the study participants was already high at baseline.

HOME BASED SUPPORT/HOSPITAL AT HOME

Seven studies (four systematic reviews, three RCTs) evaluated home based support.

Not condition specific

One review looked at nursing interventions during home visits (Frich 2003). This review, which included 16 studies (seven with older people, seven with diabetic patients and two with people with arthritis), found that although there were some patient related improvements, in general the effects on patient outcomes were mixed.

Cardiovascular

One systematic review, including five studies, (Hamner 2005) evaluated post-hospital nursing interventions for patients with cardiac disease. They found mixed results and concluded that the impact on clinical outcomes, health care costs and resource use was unclear.

COPD

Two systematic reviews focused on home based support for patients with COPD. One (Ram 2004) evaluated hospital at home schemes compared with inpatient care for patients with acute exacerbations of COPD. The review included seven RCTs with 754 participants. They found no significant difference in readmission to hospital or mortality but hospital at home was more cost-effective than inpatient care. The review suggests that patients may be safely treated at home although the reviewers point out that this is not suitable for all patients. In the other review (Smith 2001) they evaluated the effectiveness of respiratory health care worker outreach programmes for patients with COPD. They included four studies with 624 participants and in three out of four studies the intervention was provided by nurses. They found no significant difference in lung function and exercise testing, health related QoL or mortality. The authors conclude that nursing outreach programmes may be more beneficial to patients with moderate COPD but not those with more severe COPD. Two RCTs, with 374 participants, evaluated home based support. One US study (Coultas 2005) evaluated the effect of nurse-assisted pulmonary rehabilitation at home. They found no effect on health care use or health related QoL. In the other (Kwok 2004) an intensive community nurse supported discharge programme in Hong Kong did not have a significant

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impact on service use, functional and psychosocial status, or caregiver burden.

Stroke

Three RCTs, two from the UK (Burton 2005, Forster 1996) and one from Holland (Boter 2004), evaluated home based support for stroke patients by specialist nurses. In general, there was little evidence of benefit from the interventions. The two UK studies evaluated specialist nurse outreach and education for stroke patients (Burton 2005, Forster 1996). Neither study found a significant difference in functional ability or other health related outcomes at 12 months. One (Burton 2005) found a short term reduction in carer stress but this was not maintained at 12 month follow up. The Dutch study was a multicentre study (n=536) evaluating a specialist nurse outreach care programme for recently discharged stroke patients (Boter 2004). There were no significant differences in satisfaction, QoL, use of rehabilitation services, anxiety and depression, activities of daily living or carer strain.

EDUCATION/HEALTH PROMOTION

Twenty-one studies (one review and 20 RCTs) evaluated interventions that primarily involved education and/or health promotion.

Not condition specific

One systematic review and three RCTs focused on health promotion interventions. The systematic review (Rice 2004) included 30 RCTs of nurse-delivered smoking cessation interventions with a variety of populations including participants with cardiovascular disease, diabetes, respiratory disease and those from the general population. A meta-analysis, of 25 studies, showed a statistically significant effect on smoking cessation. The authors say there was some evidence that smoking cessation interventions may be particularly effective in patients with cardiovascular disease and that it may be appropriate to intervene early after diagnosis.

One US RCT (n=139) (Bennett 2005) compared theory-based nurse health related 'coaching' with TAU from primary care physicians for older adults. They found no significant differences in most health related outcomes. In a UK cluster RCT (Roderick 1997) (n=956), evaluating whether dietary advice by practice nurses could lower diet related coronary heart disease risk, they found a small decrease in the intake of total and saturated fat, a small rise in fibre intake and increases in eating healthier foods. There was little change in smoking prevalence, physical activity or blood pressure. In the other RCT (Taylor 1996) a smoking cessation

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intervention delivered by a nurse case manager improved smoking cessation rates amongst 628 American hospitalised smokers.

Asthma

Six RCTs evaluated education, counselling and/or health promotion by specially trained nurses for people with asthma. All the interventions were designed to promote self-management. The studies had a total of 767 participants although many studies were small with only three having more than 100 participants The studies were done in a variety of countries with three conducted in the UK (Levy 2000, Madge 1997, Morice 2001).

Three studies involved children. In one (n=201) (Madge 1997) they found less hospital admissions in the intervention group compared to control and a decrease in morbidity scores but no effects on ED or GP visits. A Taiwanese study (n=62) (Yang 2005) found improvements in knowledge, QoL and asthma symptoms in the intervention group at one month, but a small school based study (n=36) (Persaud 1996) found no significant difference in knowledge, attitudes, school absenteeism or ED visits at 20 weeks. The other three RCTs involved adolescents and adults; two in out-patient settings. In one Australian study (n=125) (Abdulwadud 1999) they evaluated a group based educational programme for asthma patients aged 16 and over. They found an immediate post intervention increase in knowledge in the intervention group compared to control but at six months there was no difference in knowledge or other outcomes. In the other outpatient study (n=211) comparing specialist nurse education with TAU from the GP (Levy 2000) they found the intervention group had better self-management, improved lung function and fewer consultations with health professionals. In the other RCT a two session education programme was delivered to adult inpatients by an asthma nurse (n=80) (Morice 2001). They found an increase in self-management in the intervention group but no significant effect on service use.

Cardiovascular disease

Six studies with a total of 1302 participants evaluated the effect of education and health promotion for patients with cardiovascular disease. Three studies were done in the USA (Ammerman 2003, Becker 1998, Dougherty 2004), and one each in Sweden (Carlsson 1997), Canada (Johnson 1999) and Norway (Quist Paulsen 2003). In general results were mixed. Two studies reported changes to dietary behaviour but this was not reflected in blood cholesterol (Ammerman 2006), or levels of physical activity (Carlsson 1997). One study of an education programme for the siblings of individuals with premature heart disease (Becker 1998) found a significant decrease in LDL levels in the intervention compared to control although they found no significant difference in diet and physical activity. Three studies evaluated the effect of health education on smoking. In two studies (Johnson 1999, Carlsson 1997) they found no statistically

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significant impact on smoking status. In the other study (Quist-Paulsen 2003), comparing regular contact after discharge with a control group receiving group education session, they found a statistically significant reduction in smoking cessation rates.

Diabetes

Three RCTs (New 2004, Ko 2004, Pouwer 2001) evaluated the effect of nurse run educational interventions. Although, in some cases, they found some positive effects in general the interventions appeared to have no significant effect on glycaemic control or other clinical variables. The largest study, a UK cluster RCT with 5371 participants evaluated the provision of an outreach nurse specialist education programme to practice nurses and GPs that aimed to improve hypertension and hyperlipidaemia control in their diabetic patients (New 2004). At two year follow up they found no significant difference in the number of patients achieving target blood pressure or lipid levels between intervention and control practices.

Dermatology

Two UK RCTs (Chinn 2002, Gradwell 2002) with 301 participants evaluated single session educational interventions for patients with dermatological conditions. Neither found an impact on QoL although in one the intervention group had fewer GP visits and greater knowledge about treatment at six week follow up (Gradwell 2002). A review of nurse run interventions (Courtenay 2006) provided some support for nurse education but in general little evidence of effectiveness was reported.

Rheumatology

Two RCTs of education programmes found no significant differences between intervention and control groups. In one, a UK cluster RCT, (Victor 2005) of a primary care based education programme, involving activities to increase self-efficacy and develop coping skills for patients with arthritis of the knee, no significant differences were found in health related outcomes or GP visits. The other, a small pilot study (n=32) evaluating the feasibility of a telephone self-management programme in the US (Blixen 2004) found no effect on self-management behaviours, QoL or health status.

Stroke

Two RCTs evaluated education based interventions for stroke patients. One UK RCT (n=208) evaluated a health education and counselling intervention delivered by a stroke nurse specialist compared to TAU by a GP (Ellis 2005). They found no significant differences in risk factors or depression. However, patients in the intervention group felt more able to consult staff and more satisfied that they had received adequate

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information. In a Swedish RCT (n=100) of nurse run group based support and education for spouses of stroke patients (Larson 2005) they found no significant between group differences in QoL, perceived well-being or health status.

NURSE RUN CLINICS

Nurse run clinics were evaluated in 26 studies including five systematic reviews, 18 RCTs, two controlled studies and one economic evaluation. The most frequently evaluated type of clinic was for patients with cardiovascular disease.

Not condition specific

One US RCT (n=1316) (Mundinger 2000) compared nurse practitioner clinics in primary care with TAU by a physician. Although a review of a subset of patients from the study (Lenz 2002) found that nurses were more likely to provide education and more likely to perform urinalysis and monitor HbA1c these differences in the processes of care between nurse practitioners and physicians were not reflected in the outcomes. There were no differences reported on health status; disease-specific physiological measures; satisfaction; or service use (Lenz 2004).

Anticoagulation

One UK RCT(n=224) evaluated nurse run computerised decision support and patient testing in primary care compared to usual hospital follow up (Fitzmaurice 2000). They found no significant between group differences in INR control although the proportion of time spent in the INR range showed a significant improvement in the intervention group. The intervention, however, was more expensive than the control. Two UK uncontrolled studies (Connor 2002, Taylor 1997a) found that nurses were at least as effective as doctors in managing patients on anticoagulation medication, and that the nurse service was not more expensive than the consultant led service (Taylor 1997b)

Asthma

Four RCTs, (one with accompanying economic evaluation) evaluated nurse run clinics for patients with asthma. Clinics took place either in hospital outpatient departments, in primary care or, in one case, in schools (Salisbury 2002). Two Cluster RCTs in general practice in the UK found little overall effect from the interventions. One (Griffiths 2004) involving 44 general practices and 324 participants evaluated a specialist nurse intervention. They reported a reduction in the number in the intervention group attending unscheduled care but no statistically significant difference in hospital admissions, ED or GP visits. In the other study (Premaratne 1999) nurse specialists gave education and support to help practice nurses

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set up asthma clinics. They found no significant difference in QoL, ED visits or the amount of steroids prescribed by GPs.

Two RCTs focused on children found mixed results. One (n=74), comparing nurse run outpatient care with TAU by a paediatrician (Kamps 2003) found that nurses were as effective as doctors and that health care costs were reduced (Kamps 2004). The other larger study (n=450), evaluating school-based clinics delivering care targeted at adolescents (Salisbury 2002), found a significant improvement in asthma knowledge, attitudes and inhaler technique but no significant differences in QoL, symptoms or school absence. Costs were greater in the intervention group.

Cardiovascular

Four systematic reviews (including 46 studies) evaluated nurse run cardiac clinics (Page 2005, Gustafsson 2004, Hamner 2005, Phillips 2005). In general, nurse run clinics were found to be at least as effective as care by doctors (Page 2005, Gustafsson 2004) with reductions in admissions, readmissions, mortality and costs (Hamner 2005). One review (Phillips 2005) found that complex programmes that involved hospital discharge planning were most effective. There was little information on adverse events or cost effectiveness and one review (Gustafsson 2004) pointed out that it was not always possible to distinguish between the contribution of the nurse and doctor. Facilitators to effective service provision included: experienced cardiovascular nurses with access to cardiologists, intensive follow up, comprehensive patient and family education, multidisciplinary involvement, adequate support and resources and clear pharmacological management protocols (Hamner 2005).

Five RCTs with a total of 1829 participants assessed the effectiveness of nurse-run clinics (Ekman 2003, Lloyd-Williams 2006, Mejhert 2004, Murchie 2003, Thompson 2005). The majority of participants (n= 1343) were from one study (Murchie 2003). In this UK based study they compared nurse run clinics in primary care with TAU from a GP (Murchie 2003). At 12 months they reported a significant improvement in appropriate aspirin use, BP, lipid levels, exercise and diet. At four year follow up although there was a significant difference in mortality in favour of the intervention group there was no longer any significant effect on any other outcomes. However, by four years many of the control patients had also attended clinics. Another UK study (Thompson 2005) evaluated nurse run clinic and home based follow up compared to TAU (Thompson 2005). They found no effect on mortality but a significant reduction in unplanned readmissions and length of recurrent hospital stay in the intervention group. In the other studies no significant effects were shown. This included two Swedish studies of nurse run clinics (Ekman 2003, Mejhert 2004) and a UK study of an intervention to develop and disseminate

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guidelines for use in heart failure clinics provided by practice nurses (Lloyd Williams 2006).

Diabetes

Two UK RCTs evaluated nurse run clinics for patients with diabetes and both found some positive effect on blood pressure. The larger study (n=1407) (New 2003) evaluated specialist nurse run clinics for diabetic patients receiving shared care by GP and hospital. At 12 months an increased proportion of patients in the intervention group achieved specified targets for blood pressure and lipid levels and there was a reduction in all-cause mortality. In the other smaller study (n=120) (Denver 2003) hospital based nurse run clinics for diabetic patients with uncontrolled hypertension were compared to TAU in general practice. At six months they reported an improvement in systolic BP but no effect on diastolic BP. There was also a significant fall in absolute stroke and CHD risk scores although no effect on cholesterol or glycaemic control.

Hypertension

A systematic review (Oakeshott 2003) with ten studies evaluated the effectiveness of nurse run hypertension clinics in primary care. The review found little effect on blood pressure but the authors point out that equivalence may be the desired result and nurse run care did not appear to be less safe than care by a GP.

Rheumatology

Three small UK RCTs evaluated nurse-led clinics run by specialist rheumatology nurses. Two compared care by a nurse with care by a doctor. In one (Hill 1997) patients were more satisfied with nurse-led care although in the other (Hill 2003) there were no differences in patient satisfaction or health status. However, the authors conclude that care from a rheumatology nurse practitioner is as safe and effective as that by a junior doctor (Hill 2003). In another study (Ryan 2006) comparing a consultation with a clinical nurse specialist in a drug monitoring clinic with care by an outpatient staff nurse they found no significant differences in health related outcomes. Two Dutch studies evaluating the effect of specialist nurse clinics for patients with rheumatoid arthritis (Tijhuis 2003, Temmink 2001) found that the clinics appeared to be as effective as usual hospital care.

DISCHARGE MANAGEMENT

Four RCTs evaluated discharge management.

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Cardiovascular

Three RCTs with a total of 854 participants looked at nurse managed discharge and follow up. A UK cluster RCT (n=597) assessed the effectiveness of liaison nurses to coordinate and support follow up care in general practice for patients with MI or angina (Jolly 1999). They found no statistically significant differences in outcomes at 12 months. In the other two US studies results were mixed. An evaluation of a one hour discharge education programme for patients with heart failure (Koelling 2005) found a significant decrease in heart-failure related hospitalisations and cost but no difference in mortality. The other study small study (Barth 2001) found no difference in service use but a significant improvement in QoL.

Diabetes

A Chinese RCT (n=101) (Wong 2005) compared nurse run early discharge and education for adults with diabetes to usual inpatient care. At 24 weeks they had greater exercise adherence and self blood glucose monitoring but there was no significant difference in medication adherence, glycaemic control, patient satisfaction, readmissions or ED visits.

TECHNOLOGY

Telecare or telemonitoring were the subject of one systematic review and two small RCTs. The two RCTs (Jerant 2003, Artinian 2001) found some improvements in outcomes in patients receiving telecare but, in contrast, the review (Hamner 2005) found that the effectiveness of technology-based interventions was unclear.

CONDITION SPECIFIC SPECIALIST NURSE ROLES

Dermatology

Nurse run care for patients with dermatological conditions were evaluated in a systematic review (Courtenay 2006) which included 14 studies, only four of which were RCTs. Nurses were treating a number of dermatological conditions, primarily using treatment protocols, across a range of clinical settings. In general, patients seem to be happy with the services and appreciated being able to see a nurse quickly.

Epilepsy

We included one systematic review, two RCTs and one controlled study that evaluated the role of specialist epilepsy nurses. The review (Bradley

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2001), which included three RCTs, does not give much detail about the exact nature of the nurses' role but concludes that there is, as yet, little evidence that specialist epilepsy nurses improve the quality of care. The studies reported no significant effect on frequency of seizures, depression and anxiety or sick leave or school days missed. The two RCTs (one set in Norway, one in the UK) had a total of 365 participants. The Norwegian study (Helde 2005) evaluated group education and nurse follow up compared to TAU from a neurologist and clinic nurses. They found no effect on health related QoL although there was greater general satisfaction among the intervention group compared to control. The UK RCT (Risdale 1999) evaluated a nurse run clinic compared to TAU from a GP or specialist. They found no effect on knowledge although the intervention group had lower depression score levels than the control group. Neither study measured seizure frequency. In the controlled study (Mills 1999a, 1999b) they assessed the effect of a primary care based epilepsy specialist nurse service providing a CM type intervention. Although the intervention group were more satisfied with their care and had a greater adherence to their medication they found no effect on frequency of seizures, health status, use of other health services or perceived quality of life.

Multiple Sclerosis (MS)

Two systematic reviews (De Broe 2001, Forbes 2003) exploring the role of MS specialist nurses found little in the way of sound evaluations. They describe the nurse's role which included psychosocial support, co-ordination of care, referral, provision of specialist advice and patient education.

Parkinson's Disease

We included three UK RCTs which looked at specialist nursing care for patients with Parkinson's disease. Overall there was little evidence of effectiveness. In one small study (N=64) (Jahanshahi 1994) where nurses provided home visits and telephone contacts over a six month period they found no significant differences in any psychosocial variable measured. In another larger study (n=1836) (Hurwitz 1999) they compared specialist nurses working with GPs with usual primary care. They found no significant differences in functioning and well-being, mortality or the stand up test. However, there was a significant difference in the global health questionnaire in the intervention compared to control and the average costs were lower amongst intervention patients. The third study compared care by a specialist nurse with that by a specialist neurologist (Reynolds 2000) in hospital outpatient clinics (n=185). They found no significant difference in any of the primary outcomes at 12 months. Economic analyses on a subgroup of patients found that specialist nurse care was more expensive than that by the neurologist.

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3.4.4 Barriers and Facilitators

A number of key themes, concerning barriers and facilitators around nurses and CDM emerged from the literature. These themes came from both quantitative and qualitative studies and were grouped under seven categories:

- communication and interaction between health care professionals
- the role of the nurse
- resources
- support for nurses
- education and training
- organisation and systems
- factors around the intervention.

These are discussed in more detail and are summarised in table 3.

Communication / Interaction between health professionals

A common barrier to effective working was poor communication between nurses and GPs or specialists, with nurses sometimes finding access to other health care professionals difficult (Gagnon 1999). For example, an evaluation of nurse-led clinics in primary care found that poor communication with GPs was a barrier to effectiveness (Murchie 2005) and when evaluating the success of Evercare in the UK Boaden and colleagues (Boaden 2006) highlight the importance of case managers having good relationships with GPs. Difficulties sometimes arose because of the power imbalance between nurses and doctors (Foster 2005, Gagnon 1999), with doctors reluctant to change patient's treatment at the suggestion of a nurse (New 2004). A facilitator appeared to be when GPs recognised specialist nurses expertise, trusted them to work autonomously and responded to their recommendations (Foster 2005). In some instances specialist nurses found problems meeting with, and motivating, general practice staff (Krein 2004, Mills 2002, Gillibrand 2004). The importance of multidisciplinary working was also highlighted (Boaden 2006, Hamner 2005).

The role of the nurse

One advantage highlighted by many studies was that nurses often had more time than doctors for consultations with patients (Ellis 2005, Frich 2003, Eijkelberg 2002, Hill 1997, Litaker 2003, Ridsdale 1999). They were, therefore, able to give more detailed information about the aetiology and management of conditions than doctors and had more time for education and counselling (Pearson 2005, Ridsdale 1999). Nurses were also often seen as more approachable and accessible (Ellis 2005, Everett 1998, Symons 2004, Wiles 1997). However, some nurses expressed frustrations about the limitations of their role. This was particularly apparent around the issue of prescribing and pharmacological management. Many nurses were unable to independently prescribe medication (Courtenay 2006) and this inability to prescribe or alter medication was sometimes seen as a barrier to the delivery of interventions (Eijkelberg 2002, Jolly 1999, Peters

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2000). In contrast the empowerment of nurses to alter prescriptions was seen as a facilitator (Gibbons 2001b).

A number of studies explored, in surveys or qualitative studies, the nature of the role of nurses in chronic disease management. In particular they looked at the role of specialist nurses. However, there was often a lack of clarity around the role definition (Foster 2005), and it was not clear what aspects of the role might be particularly important (Forbes 2003, Goodwin 2004). Indeed the same job title may be held by nurses whose skills and competencies varied widely (Goodwin 2004). In addition nurses were sometimes frustrated that they could not perform the role as they would like. For example they found they were spending much of their time on administrative or management duties rather than using their clinical skills (Boaden 2006, Dealey 2007).

Resources

A lack of resources emerged as one of the major barriers to service effectiveness and delivery. Insufficient funding, staff shortages, excessive caseloads and a lack of time emerged from the literature as barriers (Arnold 2004, Boaden 2006, Eijkelberg 2003, Gagnon 1999, Gillibrand 2004, Jolly 1999, Krien 2004, Mills 2002, Murchie 2005, New 2004, Pooler 2005, Tracy 2003, Wright 1999). In the evaluation of Evercare the authors recommended limited caseloads (Boaden 2006) and the need for a timely supply of equipment was also documented (Boaden 2006, Dowswell 2000, Everett 1998).

Support for nurses

A number of studies highlighted the importance of mentoring and support for nurses working in CDM (Drennan 2005, Greaves 2003, Mills 2002). In particular, mentoring and support from GPs and consultants (Boaden 2006, Murchie 2005, Anderson 2005). This was important to prevent nurses feeling isolated and unsupported (Mills 2002, Murchie 2005), to enable them to expand their existing roles (Wright 1999), and to adapt to new roles, such as that of Community Matron (Drennan 2005). Some studies also suggested that organisational and administrative support was important (Boaden 2006, Mills 2002), including adequate IT facilities (Arnold 2004).

Education and training

A key and recurring theme that emerged from the literature was around nurses' education and training requirements. Adequate training, structured education pathways (Goodwin 2004, Helde 2005), and the use of specialist nurses were seen as facilitators to effective working (Anderson 2005, Fitzmaurice 2000, Hoskins 1999, Ketalaars 1996, Levy 2000, Murchie 2005). Conversely unmet training needs were frequently cited as a barrier. Inadequate education and training could be due to a lack of funds or opportunities for training (Gillibrand 2004), or because the training that was available did not adequately meet nurses needs (Greaves 2003). In many cases nurses expressed a wish for additional training (Arnold 2004, Greaves 2003, Lip 1997). In particular primary care nurses,

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who were often involved in chronic disease management, lacked confidence and felt the need for additional training (Courtenay 2006, Greaves 2003, Pierce 2000). Some nurses also felt the need for more information about prescribing and medication issues (Wright 2001). One study around the role of the Community Matron (Drennan 2005) found that even experienced nurses could experience problems when moving from the hospital environment to the community. They highlighted the importance of adequate mechanisms for supported learning to help nurses adapt to the community environment.

Organisations and systems

It was clear from the literature that adequate organisation was a key factor. It was important that systems were in place to respond to nurse recommendations (Foster 2005). Good interface between primary and secondary care was seen as key (Levy 2000, Temmink 2001). Support and recognition from stakeholders was also seen as an important facilitator for hospital nurses moving to the community as Community Matrons (Drennan 2005). A number of problems were cited in the literature. For example: nurses unable to affect local provision (Jolly 1999), case managers who found it difficult getting involved when their patients were

Table 3. Key findings from literature mapping.

Barriers	Facilitators
Poor communication between nurses and GPs/specialists	Effective communication between nurses and GPs/specialists
Doctors reluctant to change patient's treatment at the suggestion of a nurse	Doctors who recognised specialist nurses expertise, trusted them to work autonomously and responded to their recommendations
Specialist nurses having difficulty meeting with and motivating general practice staff.	Effective multidisciplinary working
Lack of time	Nurses had more time than doctors for consultations with patients and were seen as approachable and accessible.
Lack of autonomy. Nurses unable to prescribe or alter medication	Empowerment of nurses to prescribe or alter medication. Use of medication protocols & guidelines. Adequate training.
Lack of clarity about role of specialist nurse and which aspects of role are	Need for greater clarity around skills and competencies required for

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important.	specialist nurse role.
Lack of resources: insufficient funding, staff shortages, excessive caseloads and lack of time	Resources including: protected time, limited caseloads and timely supply of equipment.
Nurses sometimes felt isolated and unsupported	Supervision and mentoring. In particular mentoring and support from GPs and specialists.
Nurses spending time on administrative and managerial tasks rather than using clinical skills	Organisational, administrative and IT support.
Nurses feeling that they lack the necessary skills because training is unavailable or not adequate.	Education and training with structured education pathways.
Poor interface between primary and secondary care	Effective interface between primary and secondary care

admitted to hospital (Boaden 2006) and different policies in health and social services which made joint working difficult (Watson 2003).

Factors around the intervention

A number of factors emerged that were seen as facilitators to the success of an intervention. In particular the intensity and duration of an intervention appeared to be important. Adequate and continued contact was cited as a facilitator by several studies (Barth 2001, Frich 2003, Hamner 2005, Levy 2000) as was continuity of care (Barth 2001, Hill 2003, Hill 1997).

These categories were not, however, mutually exclusive and there was considerable overlap between them. To facilitate and improve the contribution of nurses to CDM key stakeholders need to ensure that nurses are adequately supported and supervised with mentoring from relevant personnel. In addition, it is important to ensure good communication between nurses and other health care professionals. Education and training is vital to ensure nurses are equipped to meet the challenges of their roles and more established and formal education pathways may be needed.

3.4.5 The patient perspective

Eleven qualitative studies explored the patient perspective in some way (Boaden 2006, Eijkelberg 2002, Thorsteinsson 2002, Wilson 2005, Foster 2005, Lloyd-Williams 2005, Wright 2001, Wiles 1997, Tracey 2003, Schofield 2005, Ridsdale 2002). More details of individual studies can be seen in appendix 20. In general, a strongly recurring theme from those

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studies which considered the perspective of the patient was the social and emotional skills of nurses. Nurses were seen as more approachable and accessible than doctors. A key factor was that nurses were perceived to have more time than doctors so their consultations were less rushed and there was more opportunity for education, counselling and health promotion. Although patients generally expressed satisfaction with nurse run care some also wanted access to 'experts' such as doctors and hospital specialists. They felt that nurses were not able or equipped to deal with certain aspects of care such as prescribing or dealing with medical complications. However, although patients appreciated the expertise of hospital specialists or specialist nurses they also liked the easier access to primary care staff such as practice nurses and GPs.

3.5 Summary

Despite the number of studies many nursing interventions were not well evaluated and there was insufficient evidence to say whether or not they were effective. However, in general it appeared that nurses could provide care that was as safe and effective as that provided by doctors, although there was little data on cost effectiveness. The benefits of some of the additional nursing interventions, such as education, home based support, and the use of technology, are unclear and further research is needed. In addition, many specialist nursing roles such as those for epilepsy or Parkinson's disease have not been sufficiently evaluated.

In summary the evidence on the effectiveness of nursing interventions is mixed but key findings are summarised below.

There was overall support for the following interventions:

- Nurse-run clinics (particularly cardiovascular and anticoagulation clinics) appeared to be safe and effective. There were more mixed results for asthma clinics but this may be due to a lack of research.
- Smoking cessation programmes. These may be particularly effective in patients with cardiovascular disease and the best time to intervene may be early after diagnosis.

The following were potentially effective interventions:

- Case management and disease management for patients with diabetes although more research is needed.
- Home based support for older people. This appears to be most effective if visits are frequent and extended over time.
- Patients with COPD and respiratory disease may benefit from nursing outreach programmes and hospital at home appears to be safe. However, this is not appropriate for all patients and may be less suitable for those with more severe disease. There is less evidence of effectiveness from home based education and pulmonary rehabilitation programmes.

There was insufficient evidence and in general more research is needed for:

- case management for frail older people with chronic disease

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- case or disease management evaluation for people with asthma and cardiovascular disease
- discharge management and follow up for people with cardiovascular disease
- home based support from specialist stroke nurses
- epilepsy specialist nurses (ESNs)
- Parkinson's disease specialist nurses
- multiple sclerosis specialist nurses
- education programmes for asthmatic patients
- use of technology for cardiovascular disease
- specialist nurse services to provide support and education to primary care staff such as practice nurses and GPs
- nurse run clinics for asthma.

Studies evaluating the patient perspective within CDM suggested that patients' particularly valued the social and emotional skills of nurses, their approachability and the time available at consultations. However, while generally satisfied with nurses working within models of CDM, some patients wanted access to those perceived as experts such as doctors, and felt that nurses were often limited in what they could offer in certain aspects of care such as prescribing.

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4 Consensus Conference

The consensus conference, follow up workshop and on-line discussion of a virtual panel of nursing experts in CDM formed phase two of the project. Details of the consensus conference methodology can be found in 2.4.

4.1 Identification of Participants

Expert nurses working within the field of CDM were identified via a systematic search of UK practice focused journals and websites (see 2.3.5 and 2.4.3). From this search 70 nurses were identified but this did not include any midwives, health visitors or school nurses. While it was perhaps predictable that midwives were not identified as having a discrete role in CDM, it was more surprising that health visitors did not appear to locate their work within CDM and that school nurses with an established role in CDM were also difficult to locate by the search strategy. However, the most unexpected finding of the search was the apparent invisibility of practice nurses from general practice. Practice nurses have a well-recognised and significant role in CDM and yet only one was identified via the search strategy. This practitioner was the lead for a nurse-led surgery and it appears likely that overall the contribution of practice nurses is veiled behind General Practitioners within primary care. A snowball sampling process (Gobo, 2004) identified school nurses and practice nurses but failed to recruit any health visitors (or public health nurses). Service user representatives were identified via the project's service user reference groups or through patient organisations, their remit was to inform and challenge the discussion. A total of 47 practitioners, managers and user representatives attended the conference (table 4).

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Table 4 Roles of Participants Attending Consensus Conference

Role	**Numbers**
Case manager/community matron	11
Consultant nurse in LTCs	2
Specialist nurse in epilepsy	2
Specialist nurse in respiratory conditions	4
Specialist nurse in multiple sclerosis	2
Specialist nurse in Parkinson's disease	2
Specialist nurse in diabetes (adult and children)	2
Specialist nurse in heart failure	2
Specialist nurse in continence	1
Specialist nurse in cystic fibrosis	1
Specialist nurse in Children's rheumatology	1
Specialist nurse in Children's Asthma	1
School Nurse	3
Practice nurse/nurse practitioner	4
Programme Director for LTC's	1
Lead nurse for district nurses/community matrons	3
Head of Health Improvement	1
Service user with arthritis	2
Service user with diabetes	1
Service user with osteoporosis	1
Total attending	**47**

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4.2 Themes from the consensus conference

4.2.1 What is the nursing contribution?

This descriptive stage of the project allowed for the identification of recurring themes from the presentations and discussions from the consensus conference, and indicated that nurses are undertaking a range of roles in the area of CDM. Nurses perceived that they had the ability and willingness to multitask both within their profession and across professional boundaries more effectively than other health professionals and often at less cost to the service.

Accounts were given that highlighted the persistence of the marginalisation and invisibility of the nursing contribution within organisations. Nurses were on occasion, only supported in their roles because they were perceived as being a cheaper resource than other professionals. Some presenters also highlighted the pressures they were under to demonstrate that they represented a cost saving, often without due consideration to the quality of the service they were providing.

Participants indicated that the nursing contribution brought a number of benefits for patients. First, from a resource perspective, nurses argued that in comparison to other professionals they had more time to offer patients. Second, nursing was seen as more likely to provide continuity of care and carer for the patient. Third, while nurses voiced a strong empirical & professional base to their work, it was perceived that there was more equality in their relationship with patients than other health professionals and from the patient's perspective were felt to be more accessible.

The patient perspective was identified as central to organisation of their practice for the majority of nurses. Presenters indicated that core aspects of their work included the translation of medical jargon, being skilled at assessing the wider picture and addressing psychosocial issues and the development of a therapeutic relationship which has more the feel of a "friendship". Many practitioners argued that nurses more than other professionals facilitate the articulation of the patient voice in health care decision-making. Conference presenters felt that nurses were *the* professionals who could most easily convey clinical knowledge in an accessible format for patients. The nurses working with children and young people provided examples of the value of a relationship that offered patients with a means to access knowledge about their conditions. Young people with LTCs not only have needs for information about their condition, but also have needs that change over time particularly in relation to the management of their condition during puberty. Nurses were felt to have established trusting relationships that enabled young people to ask for and access the often very sensitive information they needed. Many

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of the roles also had a strong educative element, in particular, 'teaching' patients how to recognise deterioration in their condition and take appropriate self-care action.

However, despite the participants' consensus on qualitative outcomes of their contribution to CDM, a number of issues were acknowledged surrounding measurable outcomes. In particular, a lack of clarity nationally in defining a "saved admission" was identified along with the problems on having a focus on this as the major outcome. Multi-determinants of health that impacted on admissions but were not addressed in the Quality and Outcomes Framework (QOF) were highlighted. In addition it was acknowledged that effective case finding by nurses may initially raise costs by uncovering previously unknown patients to the service.

The flexibility and adaptability of nurses to carry out a number of roles within CDM was continually acknowledged and there was consensus that other health professions were unable to offer similar multitasking ability that was underpinned by a holistic approach.

4.2.2 Enabling factors for an effective nursing contribution

A number of enabling factors were identified by the participants. Organisational preparation for new roles was acknowledged as vital and this included a careful "preparation of the ground" and the involvement of other health professionals and departments from the start.

Organisations that fostered trust between the primary and secondary care, particularly where there was integration of LTCs' planning and services across all agencies were seen as a powerful enabler of effective nurses' roles.

The support of other professionals and the development of multidisciplinary teams (MDT) made up of complementary personalities was also identified as an enabling feature.

4.2.3 Barriers to an effective nursing contribution

From an organisational perspective the current uncertainty of reconfiguration was recognized as a barrier. Participants also voiced a less effective contribution if there was a lack of other provision such as falls and stroke services. Issues around information technology (IT) often emerged, particularly incompatibility between services and a lack of time or administrative assistance in maintaining records. Duplication of notes between services was also highlighted as problematic.

Professional rivalry was seen as potentially challenging particularly when new roles were not understood. Often this was felt to result in appropriate patients not being referred on to the nurse.

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4.2.4 Issues Specific to Each Nursing Group

***Community matron/case manager*:** Despite some local variation the case management role had originated mainly in response to Department of Health initiatives (Department of Health, 2005d). Many case managers were relatively new to their role and were having some difficulty in accessing training. There was some concern voiced about having to constantly prove their worth and achieve the narrow focus of bed days saved. Many suggested that psychosocial issues and the lack of resources to deal with them rather than deteriorating physical condition were the main cause of hospital admission. This view was echoed in all the nursing groups.

A facilitative context for case managers was identified as close engagement with social services and the support of a committed manager. In addition a local effective mentor such as a nurse consultant and a learning network were reported as particularly enabling and this appears to work very well where local PCTs have pooled resources.

For those case managers who had been longer in post there was some evidence presented that hybrid tools for patient at risk identification were being developed, this was often as a response to a generalised concern that the Patients at Risk of Readmission (PARR) tool was not sensitive enough.

Condition specific nurse specialists: On the whole these roles had originated in response to local needs and in some cases due to the lack of a doctor with a special interest. However, a common trigger for these appeared to be a powerful "patient voice" such as the Multiple Sclerosis Society. Such organisations had often lobbied for the development of the role, provided some key aspects of training and raised funds for vital equipment. Patient voice was not only seen as a role trigger with this group of nurses but was also perceived as an essential resource in training. Particular barriers appeared to be frequent problems in crossing the secondary/primary care boundaries.

Practice Nurses: CDM has increased significantly as part of the practice nurse's role, with a major trigger identified as the new General Medical Services (GMS) contract and QOF (Department of Health, 2004c). Participants had often received extra training in a number of conditions and were able to deal with a range of co-morbidities. GP practices, where training was facilitated, was seen as particularly enabling, as was a context where the practice nurse was valued as a highly skilled member of the team. There was some evidence presented that practice nurses were further developing their role into case management, particularly in areas where there were a lack of PCT provided case managers.

Nurses involved with younger people: Presenters expressed the view that there was insufficient recognition of the holistic nature of the outcomes of nursing work in the field of adolescent and child health. Work in this field necessarily requires work across the range of environments of the child, notably the family and school. The result is that nurses may

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undertake effective prevention and crisis management work with parents and siblings or enable the school system to respond to a child's needs effectively but this work may not be accounted for through unsophisticated outcomes measures such as hospital admission figures.

Although nursing work has suffered from invisibility within health care systems, the relative powerlessness of the patient group was felt to have an associated marginalising effect on work in the field. Working with young people was felt to be 'just the kiddie stuff' and therefore likely to be both marginal and invisible to their managers.

4.3 Consensus follow-up workshop

The consensus conference identified key areas of practice that should be encompassed by the case study sites (outlined above). These reflected key areas of nursing contribution to CDM as well as offering opportunities to explore a range of patient experiences. In the selection of the case study sites the consensus conference also enabled pragmatic issues to be explored with participants thereby adopting suitable research sites that would be able to provide access to the research team. The potential sites were drawn from the analysis of the researcher and patient representative reporters' feedback from each presentation session. Representatives from each potential case study site were then invited to the follow up workshop. The workshop allowed detailed and focused discussion of the themes from the consensus conference. Additional details on the selection for attendance at the follow-up workshop are described in 2.4.5. The workshop was attended by 15 nurses representing the following areas of CDM and geographical areas (table 5).

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Table 5. Roles of Participants Attending Consensus Follow-up Workshop

School Nurse	South England
Respiratory Nurse Specialist	South East England
District Nursing Lead	Midlands
Transition Nurse Specialist	South England
Active Case Manager	North West England
Epilepsy Specialist Nurse	Midlands
Senior Diabetes Nurse	Midlands
Programme Director LTCs	North West England
Nurse Lead	East England
School Health Advisor	Midlands
Lead Nurse for Primary Care	Wales
Senior Nurse	North West England
Nurse Practitioner	Midlands
Head of Health Improvement	North East England
Heart Failure Nurse	South East England

4.3.1 Key Elements of the Workshop Discussion

The discussion at the follow-up workshop generated refinement of the themes that emerged from the consensus conference and in particular assisted with the process of establishing the criteria for case study selections and areas for consideration during the fieldwork phase of the project.

In terms of choosing the case study sites participants were for example, critical of the lack of fit between nursing roles and the delivery systems to population groups with LTCs (Department of Health, 2005a) At that time the Kaiser Permanente pyramid (Department of Health, 2004a) was drawn upon to aid LTC population risk stratification and it was felt by participants to suggest boundaries that in reality did not exist. It was also felt that integrated teams were key to CDM and that part of the research should investigate what skills & training the teams need. Finally it was felt to be important for understanding the nursing contribution for the research to tease out the difference between case management & community matrons.

A number of issues also emerged relating to the patients' perspectives that were felt valuable in terms of informing the fieldwork notably:

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- the need to recognise that hospitals are often preferred place of care by patients and carers dealing with complex home circumstances
- Patient-led also means individual risk, one size does not fit all
- the need to recognise carer need as well as patient need.

4.4 International Panel Consultation

As part of phase 2 an on-line discussion on nursing models of CDM was set up with international experts in the field. Six experts from Canada, Australia, Iceland and Spain contributed to an on-line discussion on a dedicated website. The discussion room opened on 1st February 2007 and continued until the second week of April 2007. Trigger questions were offered to participants as were key documents related to the project.

Participants were:

1. Sally Thorne *(University of British Columbia, Canada)*
2. Sally Wellard *(University of Ballarat, Australia)*
3. Barbara Paterson *(University of New Brunswick, Canada)*
4. Debbie Kralik *(Royal District Nursing Service, Australia)*
5. Árún K Sigurðardóttir *(University of Akureyri, Iceland)*
6. Jose Miguel Morales *(School of Public Health of Andalucia, Granada, Spain)*

***Trigger questions**:* The following were used as stimulus for the online expert panel to discuss.

1. What are the key similarities and differences in nurses' roles in CDM between the UK and your country?

2. Preliminary findings from our mapping of the literature suggest that there are particular issues in the following areas:

- nurses substituting for doctors
- the level of autonomy the nurse has
- whether the nurse is able to prescribe drugs
- the level of training and experience required for the different roles in CDM.

Do these findings reflect any issues in your country?

Findings from the international panel

The following issues were identified from a qualitative thematic analysis of the discussion and were used to iteratively inform the fieldwork strategies and questions asked within the case study sites.

The contribution of nursing to CDM represented an emerging area of global debate that was seen in the majority of countries as cutting to the heart of how nursing was likely to be defined in the future. In particular the preservation of a unique nursing perspective as opposed to becoming substitute doctors was a feature of the commentary across the countries. Nursing was identified in many countries as having a unique and defining role in relation to primary health care and the management of LTC's.

In contrast to the UK, many countries (for example Canada, Spain, Australia) had considerable differences between states/regions in legislative frameworks and nursing practice. Therefore there was less likely to be a unified national approach to CDM. In some of the countries there was a continuing emphasis on hospital-led condition specific care that prevented quality programmes being developed in relation to 'every-day management' of LTCs.

All contributors highlighted the considerable diversity in the level of educational preparation for nurses working in CDM. In some countries such as Canada and more recently Spain there were post-graduate programmes that provided a "solid cadre of Clinical Nurse Specialists" (Canada) and community nurses with advanced primary health care roles (Spain).

In all countries, CDM continues to be largely medically driven, with nursing "fitting" into the system. The development of the nursing contribution has often been opposed by other professionals and especially medical practitioners. A notable tension centred on the issue of nurse prescribing, even nurses with post-graduate specialist qualifications often did not have prescribing authority. Although again the position varied with some nurses having full diagnostic, treatment and prescribing authority. It was not universally purported that nurses held a patient-centred perspective and that in the main the health care system did not support self management:

"many people dread hospital admission and will usually do their utmost to avoid it precisely because the inflexibility of the health approach means that self care knowledge is negated."

There was scant evidence internationally of the effectiveness of nurses when working with people with chronic illness and a need for more systematic evaluation of the nursing contribution was identified.

4.5 Summary

A total of 47 expert nurses working within the field of CDM identified via a systematic search of UK practice focused journals and websites, and service user representatives invited via key user organisation and expert patient networks, attended a consensus conference. The aim of the conference was to refine and extend the debate around the nursing contribution to CDM, capture some of the temporal dynamics of the nursing contribution to evolving CDM models, and to contextualise the international models of CDM for the NHS context.

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This descriptive stage of the project allowed for the identification of recurring themes from the conference presentations and discussions. The themes included the ability of nurses to multitask within and across health professional boundaries, being viewed as a potentially cheaper resource within CDM, and having more time, accessibility and continuity of care for service users. Organisational preparation for new roles, trusting relationships between health and social care sectors, and effective multidisciplinary roles were all seen as enabling of the nurse's role within CDM. Barriers included a lack of other service provision such as falls services, incompatible IT systems between sectors, and professional rivalry.

In the selection of the case study sites the consensus conference enabled pragmatic issues to be explored with participants thereby adopting suitable research sites that would be able to provide access to the research team. The potential sites were drawn from the analysis of the researcher and patient representative reporters' feedback from each presentation session. A total of 15 representatives from each potential case study site were then invited to the follow up workshop. The workshop allowed detailed and focused discussion of the themes from the consensus conference, and enabled selection of the final case study sites.

Simultaneously to the workshop an on-line discussion with a panel of experts from Canada, Australia, Iceland and Spain took place. This explored the key similarities and differences in nurses' roles in CDM between the UK and their respective country, and how the themes emerging from the consensus conference reflected issues in their country. The contribution of nursing to CDM represented an emerging area of global debate that was seen in the majority of countries as cutting to the heart of how nursing was likely to be defined in the future. In contrast to the UK, many countries had considerable differences between states/regions in legislative frameworks and nursing practice. Therefore there was less likely to be a unified national approach to CDM. All contributors highlighted the considerable diversity in the level of educational preparation for nurses working in CDM, and that CDM continues to be largely medically driven, with nursing "fitting" into the system. There was scant evidence internationally of the effectiveness of nurses when working with people with chronic illness and a need for more systematic evaluation of the nursing contribution was identified.

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5 Case studies

This section provides the 'results' from each of the case studies within a whole systems framework. We use the term 'results' cautiously as what follows is more of an in-depth description of the political and social context of the case studies within which we have described and discussed the interaction between the patient/carer experience of the model, the organisational, data and causal systems. It is by attempting to reach an understanding of the enabling and inhibiting mechanisms for CDM within the whole system that we have reached some reasoned conclusions about the different ways in which nursing contributes to CDM. Through the survey data from each case study we have provided further complementary evidence of the quality of life, health service utilisation and cost of the models that we describe in sections 6 and 7.

As highlighted previously, the case studies discussed are identified by the models that are represented and include primary care (practice nursing), public health (school nursing), case-management (community nursing) and nurse specialist (epilepsy and diabetes). This range enabled us to explore the models themselves and their enabling features with regard to the patient/carer experience rather than to focus on disease categories. Our justification for this is that in terms of the development of services and the best use of resources, it is the model of care delivery that is most likely to determine the patient experience and outcomes, not the disease itself. Thus it might be argued that enabling features of a specific model might be applied to any chronic illness. Each case study is described in depth with the associated evidence as quotes presented as spoken from patients, carers, parents and practitioners. We have also drawn on policy literature, local and national data to inform our understanding of the context of the models.

Arguably it is the user experience that is the most important part of the whole systems framework, and has recently been identified through the Darzi Report (Department of Health, 2008a) as a key factor in quality improvement in the NHS. If the networks, organisation and data systems do not work in such a way as to improve the user experience and improve and promote health then there must surely be components of the whole system that are not functioning effectively and safely. Equally, within a whole systems framework the user experience should provide continuous feedback into the system to enable quality improvement that responds to the user and their overall experience and outcome. Clearly, to achieve this data systems and management also need to be adequately in place such that each component in the system can respond to new stimuli.

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5.1 The public health model

Poor health during childhood and adolescence can have long-term effects on life chances, by preventing the attainment of educational goals and restricting psychological development (Currie *et al*, 2008). The Chief Medical Officer's report (Donaldson, 2008), recommended that in the light of the significant effects of poor health during the teenage years '*new approaches are needed to make health programmes and health services more teen-centred*.' (p15).

Diabetes, asthma and epilepsy represent the three most common long-term conditions that affect young people. In 2002/3, there were 149,373 admissions for 10 to 19 year olds across these three conditions in the UK, just 5 years later in 2006/7 this has increased to 169,239 admissions, just over 13 percent. Asthma admissions increased by 11,291 (19 percent) over the same period. A recent study of asthma in school aged children in two UK cities found strong evidence that peaks in hospital admissions coincide with the end of the summer school holidays and the return to school (Julious *et al,* 2007). The reasons for this are not yet apparent, but the management of asthma within the school setting is likely to also merit further attention.

The significance of the school environment as a setting for effective health promotion work with children and young people is increasingly being advocated (World Health Organisation, 2000b). However health-related work in schools is far from straightforward as competing and diverse demands on the education system may result in schools and teachers feeling ill-equipped to deliver public health messages. Equally, children with a long-term condition such as asthma are experiencing transitions between health and illness, normality and maturation.

The model examined in this section is the practical operation of a model of public health leadership, which enabled school nursing to develop and implement a strategic policy for asthma management within multiple schools across one PCT in the West Midlands.

In this PCT context, a broad definition of public health can be seen to be one that promotes the education and awareness of asthma across the NHS and education systems to improve respiratory health and prevent acute asthma attacks and child mortality from asthma. This was put into action through the PCT wide asthma strategy described in 5.1.2. This might be perceived as a rather traditional model of public health that has emphasis on disease prevention rather than on the determinants of the disease, such as poverty and inequality, air quality and housing, that proponents of the 'new public health' would support (e.g. Ashton and Seymour, 1988). The Public Health Report for 2007 from the PCT[2] does record the air quality for the area stating that the site is well above the mean in the UK for both nitrogen oxide and small particle emissions. Both of these

[2] The full reference has not been given as this would identify the case study site location.

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emissions can have a harmful effect on the respiratory system, nitrogen oxide having a particular effect on people with asthma. The higher than average levels are attributed to the industrialised nature of the site and the major motorway that runs close to the site. A study by Walters *et al* (1995) found that nitrogen oxide levels in the West Midlands were significantly associated with hospital admissions for respiratory illness in the under fives. They suggest that nitrogen oxide levels might be responsible for either the prevalence or the severity of childhood asthma in the region. A more recent study (Price, 2007) has found a significant relationship between respiratory tract conditions (typically asthma and COPD), particle emissions and meteorological factors such as humidity, temperature and dew point in this PCT area. Thus while it is notable that the asthma awareness strategy did not appear to focus on this aspect of public health, its emphasis on the whole school population rather than individual children does mark it as a public health approach.

5.1.1 The PH case study site

The mainly urban borough is within the West Midlands. Table 6 shows only a small growth anticipated in the population of the borough by 2016, the number of births is predicted to remain the same and the number of 10 to 19 year olds may fall.

Table 6. Population and births.

West Midlands Borough	2006		2016	
Population of 10-19 year olds (rounded)	40,000	13%	35,000	11%
Total population (rounded)	305,000	100%	311,000	100%
Births per year	3,300		3,300	

(Office for National Statistics, 2008a)

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Table 7 highlights the high population density of the borough, ten times that of England.

Table 7. Demographics of borough

	Borough	England
% ethnic minorities	8.4	9.1
Average population density (persons per hectare)	31.2	3.8
% people of working age in employment	75	75

(Office for National Statistics, 2004a; Office for National Statistics, 2004b; Office for National Statistics, 2008)

General health of the local authority area

Life expectancy is similar to England for males & females, however the infant mortality per 1000 live births and the percentage of low birth weight babies are both slightly higher than the national average. (Office for National Statistics, 2007a; Office for National Statistics, 2007b; West Midlands Public Health Observatory, 2008)

Within the borough a number of key health indicators are significantly worse than the England average; deprivation, income deprivation (percentage of residents on means tested benefits), homelessness, teenage pregnancy, GCSE achievement, male life expectancy, percentage of school children who are obese in reception year, healthy eating adults, physically active adults aged 16 and over, people diagnosed with diabetes, percentage of mothers initiating breast feeding (just under 50 percent) and the proportion of obese adults (Association of Public Health Authorities, 2008).

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Prevalence of childhood asthma in the PCT area

Reliable prevalence data for childhood asthma in this PCT site are not readily available. However the Lifestyle Survey[3], 2006 and asthma register numbers give some indication of prevalence. This probably under-represents the true prevalence as asthma is under-diagnosed in primary care. (PCT, 2009)

- Prevalence is reported between 10 to 15 percent in all school aged children, equivalent to 6000 to 9000 children in the PCT area.

- In the Lifestyle survey[4], 2006, 15 percent of 9, 10 and 11 year olds report having asthma, while 16 percent of 12, 13, 14 and 15 year olds report having asthma.
- According to data from the West Midlands Public Health Observatory (2008) there were 159 hospital admissions for respiratory tract infections in children aged 0 to 14 in this PCT area in 2006/7 and 153 emergency admissions for the same aged children during the same period with respiratory tract infections. These data are not broken down into the actual number of children admitted with asthma but figures would suggest that despite poor air quality the hospital admission rate for children with respiratory infections tends to be lower than surrounding PCT areas with similar geographical and population profiles.

5.1.2 Origins of the model

The origins of the PCT Schools Asthma Strategy began pre-2000 when a group of community based nurses tried to set up a service to meet the needs of school-aged children with asthma. However, this was only taken forward strategically when the current asthma coordinator, herself a school nurse, came into post in 2000 and was able to take on a leadership role (or championing) in developing and managing the strategy. The initial stimulus for the eventual emergence and ratification in 2003 of the Schools Asthma Strategy appears to have been both a response to develop a more organised and efficient approach to managing childhood asthma that would reduce absenteeism from school, hospital admission and empower children and their families to manage asthma confidently. There was also a clear imperative to provide education and awareness at the school and family level about asthma in order to reduce preventable asthma related mortality in young people. The charity Asthma UK was

[3] The full reference has not been given as this would identify the case study site location.

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supportive of the initiative and provided 12 months funding for the asthma coordinator which was subsequently taken on by the PCT.

The nurse led model was established as a PCT driven model that worked across all schools in the PCT area (approximately 110) and was based on a public health approach of increasing awareness and education of schools staff, parents, children and health service staff. This public health approach was evident through the collaborative working across agencies including health, education, voluntary sector and the community as well as within the health sector where emergency departments, GP practices and hospital inpatient departments were involved. The model was (and still is) led by the asthma coordinator (a school nurse) who is PCT based and implemented via a team of school health advisors. The school health advisors are each responsible for a number of schools across the PCT and are themselves supported by schools-based asthma support workers. The coordinator and each advisor carries a caseload of children with asthma as well as the schools based and policy related role. The lead coordinator is a registered nurse and sick children's nurse as well as a school nurse and most of the advisors are registered as school nurses. The support workers could be teachers, first aid workers or teaching assistants. All have had specialist training in asthma management and have continuing professional development in this area.

Several key features of the policy have developed since its initial ratification in 2003 that have contributed to the overall success of the model.

1. Asthma Friendly School status – this is awarded as part of the National Healthy Schools Standards. The PCT was already well ahead on the criteria for meeting the National Healthy Schools award and introduced the asthma standard. By early 2008 about 50 percent (55) of all schools in the PCT had achieved Asthma Friendly status. This includes staff training in asthma, visibility and accessibility of inhalers, children independently managing their own inhalers, trigger avoidance (e.g. appropriate animals in the classroom).

2. Availability of emergency inhalers. Emergency salbutamol inhalers (asthma symptom relievers) are available in many of the local schools. This means that a child who is having serious or life threatening breathing difficulties during school time and does not have their own inhaler available can have access to emergency medication. This has been a challenging development because the medication is not prescribed for an individual child, therefore the provision is outside of usual prescribing practice. However, this is confidently managed by the asthma team through a well-developed and approved risk management tool and the support of the prescribed inhalers by a community paediatrician. The PCT has approved the procedure. The asthma coordinator states that the emergency medication is well justified on the grounds of:

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- life saving availability
- reduced call out of ambulance service and hospital admission
- reduced parental anxiety and loss of work time
- reduced child anxiety and distress
- reduced absenteeism from school
- increased parental and child confidence in school asthma procedures.

An audit of the use of the inhaler is conducted each year and between January 2006 and December 2006 it was used 106 times. As well as identifying (although not quantifying) the above justification, the audit also enables the asthma advisors to identify which children are attending school without their inhalers and to work with the families on asthma education and management.

3. Production of an Asthma UK funded asthma education pack for and by young people. This pack, which includes a DVD adopted nationally by Asthma UK, was initiated by the coordinator from her observation that young people are often over-looked in asthma care. It aims to both educate and empower staff and young people and their families about asthma management. The key feature of the pack is the integral involvement of young people in its development. This commenced with focus groups of young people providing their experiences and strategies with their asthma through to the actual production and narration of the DVD. The pack is provided to all schools, school nurses and many practice nurses and GPs have also benefited from the information. The coordinator describes how GPs who have become somewhat weary of treating young people with asthma have been completed re-energised by the voices of the young people on the DVD. As the coordinator describes, this has given young people with asthma a voice.

5.1.3 The public health model and the whole systems framework

Intuitively it would be expected that a public health model would have a good 'fit' within a whole systems framework. This does depend to some extent on how public health is defined and how the model is operationalised within the PCT context. As outlined above, the public heath model implemented here is based on disease management and prevention of acute illness and mortality through a process of awareness raising and education rather than a wider health promotion and prevention strategy involving agencies such as housing and environmental health.

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The public health model adopted in the PCT can be mapped against the whole systems approach as shown in figure 2. The elements of the system in relation to the public health model of asthma management are discussed below. By starting with the experience of the child and their parents we then go on to show how this has been impacted upon by the other parts of the system and thus how the nursing contribution to this 'whole system' in this PCT can be constructed.

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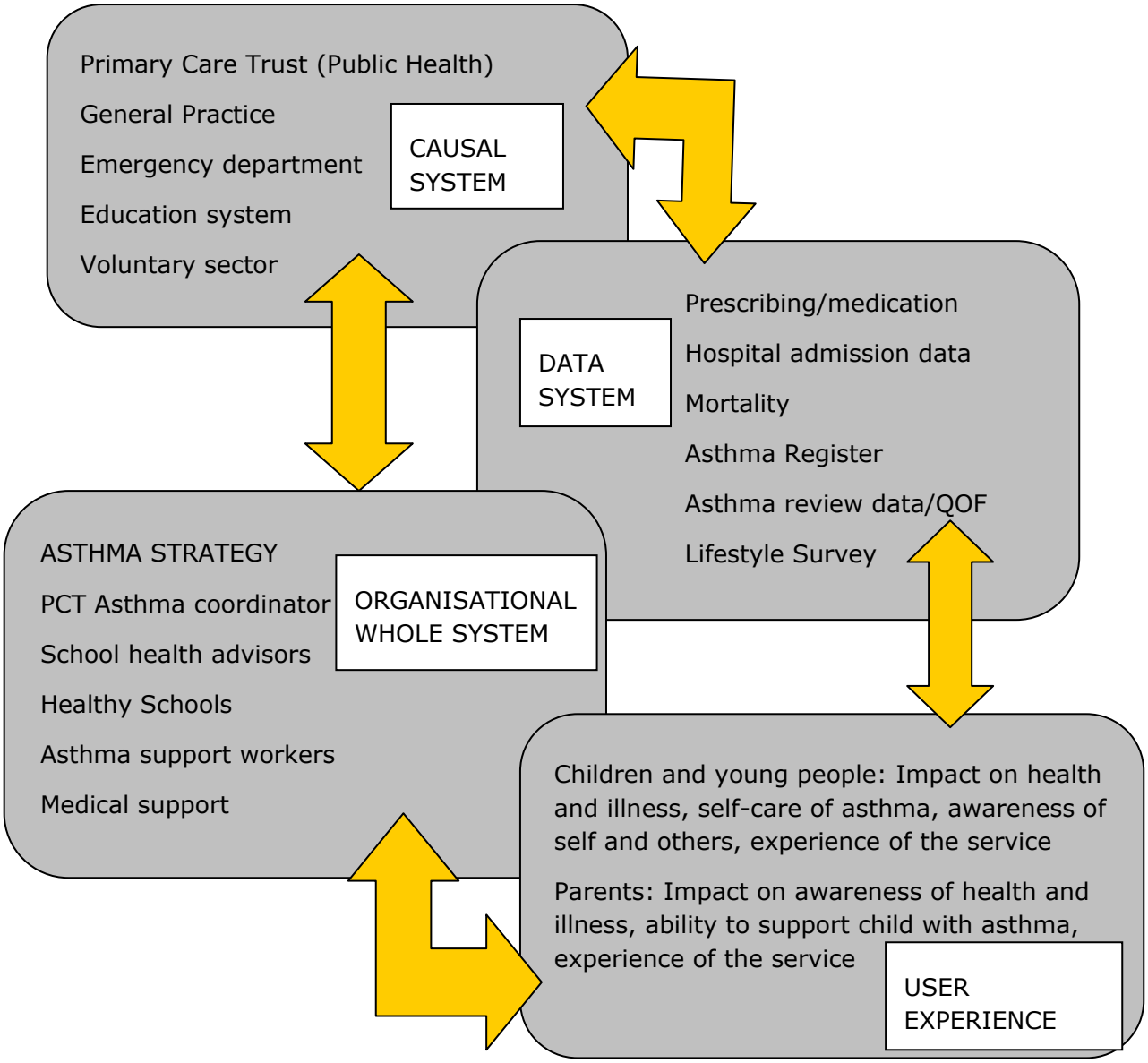
Figure 2 The public health model and whole systems framework



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5.1.4 The user experience

This section discusses the user experience of the childhood asthma strategy in this PCT from the perspective of parents and children. This is achieved through the process of the qualitative interviews, focus groups and survey data that were collected and analysed in this site, alongside any documentary evidence that was available to us.

Service users in this case study can be considered to be children, young people and their families but also teachers, school support staff and voluntary workers. As users these groups of the PCT population have access to and are provided with education and awareness training for asthma, individual advice and treatment either at school or at home and emergency care where this is necessary. The model also provides a level of communication between school and the health service that may not be immediately evident to young people or their parents but provides a level of 'invisible' care that might not otherwise be available.

Parent interviews: Four parents of six children with asthma within the PCT/schools area were interviewed by telephone. All interviews were conducted with mothers and each lasted approximately 20-30 minutes.

Profile of interviewees

Parent 1; mother of two girls, 11 to 13 age group with mild asthma.

Parent 2: mother of boy, 7 to 9 age group with relatively severe asthma

Parent 3: mother of girl, and boy (5 to 8 age group) with mild asthma

Parent 4: mother of boy, 8 to 10 age group with moderate asthma.

The data analysis was based on a very small sample of parents. Despite having invited all parents of the 328 children to take part in the survey, only four parents responded positively. As this data collection period also fell close to the school holidays it became increasingly difficult to contact either the children or their parents. Although it is acknowledged that these data are to some extent limited, nonetheless the parents who were interviewed provided some interesting and important insights into asthma management across the health and education sectors. The length and depth of the interviews did, in fact, enable saturation to be reached. The following themes emerged from these interviews:

Trigger factors

All the parents interviewed were able to identify the trigger factors that exacerbated their child's asthma. They were all confident and knowledgeable about these factors and felt able to communicate with school about the triggers they were concerned with, indicating that

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schools from the parental perspective are accepting of this range of trigger factors, which would require different responses from schools.

> *' ..my daughter the way it started, she just got lots of coughs and colds and like a night time cough and then it just basically went straight to her chest. My son, obviously he was quite similar, you know got a couple of coughs that went straight to his chest, but obviously he had hayfever….that actually affects him, …he gets like an allergy induced asthma, where he can go out like on the playing field with like grass, and that can start him wheezing. And also if he gets very stressed and he gets himself worked up, that makes him wheeze as well' Parent 3*

The data illustrated how different children with asthma are not a homogenous group with one disease, but heterogeneous with very different triggers to asthma symptoms.

Use of medication

All parents were aware of the medication requirements of their children, the frequency with which it was needed and emergency application of inhalers in school.

> *'he's obviously got Becotide brown inhaler, and the ventolin inhaler[5], which is the blue one, and he obviously has got a spacer which he has, you know, to have both of them in. …..if he starts to get a bit…you can tell he's got a cold coming on, and I start with the becotide, and just give that twice a day, morning and night. And then obviously if he does start to wheeze, that's when we start with the ventolin and give it as many times as he wants it during the day. He has actually got one at school as well, he's got a spacer and a ventolin inhaler at school' Parent 3*

Parents seemed confident in their descriptions and decisions about medication. They seem to know when to administer the medication appropriately and when other emergency drugs such as antibiotics and steroids are necessary.

> *'He'd had an inhaler in school since he was in reception class and he'd never, ever used it in school.* (that would be the ventolin, the blue one?) *..the blue one, he'd never used it in school, so from reception and he's just finished year four, he'd never used it, but she* (school nurse) *insisted that one went back into school, so I did as she said*

[5] Medication for asthma usually includes two types of inhalers. These are either relievers or preventers of asthma symptoms. A reliever is used in the immediate or short term and will most often be a bronchodilator such as salbutamol, frequently prescribed under the label of Ventolin in a blue coloured inhaler device. Preventer medication has a longer term action and consists most commonly of corticosteroids that prevent swelling and irritation of the bronchioles. These are often prescribed under the label Becotide and supplied in a brown coloured inhaler device. See www.nhs.uk/Pathways/asthma/Pages/Treatment.aspx for further information

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> So you said you resisted the Becotide, is he not using the brown one.?
>
> *He's not no'. Parent 4*

Parent 4 stood out from the other three parents in that she was more resistant to any medication and had felt under pressure by the nurse to re-introduce ventolin at school even though, as she points out on several occasions, her son had had no need of it since reception class. This demonstrated a more activated approach than the other three parents who seemed more willing to accept the necessity of regular medication, shown particularly by parents in the use of the word 'obviously' on several occasions indicating that this was the accepted norm. However, parent 4 had reluctantly accepted the advice of the school nurse in the end.

Parents also seemed aware and accepting of the school emergency procedures.

> *'Obviously you've got to give your consent when you fill in the various forms…but if there was something like that, you've given your permission to take him straight away somewhere in the car, but there's no other thing I'm aware of that they do at school'. Parent 2*

However, only parent 4 made direct reference to the back-up reliever inhalers that have been placed in the schools as part of the policy, and this was probably because she herself worked in a school. Even though the reliever inhaler provided in a life-threatening emergency at school would not be the actual medication prescribed for their child, parents did not appear to be aware of its availability referring more to the child's own inhaler or the calling of emergency services.

Family history and support

Most parents described some aspect of family history related to asthma that was either related to asthma in other siblings, parents or grandparents. For these parents such associations did not appear to them unusual and seemed to form part of their explanatory framework for their child's asthma. Thus almost a sense of inevitability was apparent; asthma was part of the family and something they had to get on with.

> *'See, I've had asthma since I was about two…so I know most about it really…….I suppose if you hadn't got asthma yourself, then it would be quite a problem you know, because you've got to get used to it haven't you?'. Parent 1*

Although this was a very small sample of parents, it is of interest that all four have some sort of family history of asthma. This could be why, as will be discussed, these parents seemed relatively confident in managing their child's asthma and in their use of the services. Asthma in their own children seemed to be explained more by the family history than any other factors. Nobody mentioned the air quality in the area or smoking in the family as possible contributory factors, apart from one parent's brief

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reference to her mother's emphysema, which she quickly dismissed as being different because it was to do with smoking.

Parents also spoke of the way in which the family history and experience of asthma enabled family members to support the child with asthma:

Use of health services

All parents interviewed had made some use of the health service in relation to their child's asthma, although this was not always recent. In some instances health services had been accessed in the early stages of the asthma when the children appeared to be less stable in their treatment. For example, parent 3 says:

> *'Before he actually got diagnosed properly, he basically had a couple of episodes where he was quite wheezy….I think the doctor sent him straight up the A and E department, children's department , and he actually had steroids, but they only kept him in for the day to observe him…'. Parent 3*

More recently, hospital admissions were the exception rather than the norm. It was more often routine visits to the GP or practice nurse or occasional emergency GP appointments, or sometimes NHS Direct.

Parent 4 again was dissimilar to the other parents in that whilst she used the health services fairly regularly she remained somewhat resistant to the advice and seemed reluctant to accept that her son had asthma.

> *'... we had an invite to the chest clinic with the nurse, and that was at the beginning of April... I actually felt a little bit pressured to put xx back on an inhaler where I hadn't really seen him struggling, breathing….But the nurse really wanted him to go onto a brown inhaler everyday, and I said well I'm a little bit anxious about this. She listened to his chest, she said he was clear, she couldn't detect anything, and I kind of resisted the brown inhaler….' Parent 4*

Overall the parents seemed satisfied that the health services were there when they needed them and they had access to medication and asthma review. None of the parents spoke of recent or frequent hospital admission. Parent 4 was likely to be most challenged by the health service but also the most challenging because she was not prepared to accept everything she was told or given.

School

Three out of the four parents were satisfied or actively pleased with the way in which their child's asthma was managed in school. While as mentioned above there did not seem to be explicit understanding of the emergency inhaler access, they did seem pleased that there were people in school who knew what to do and helped their children with their medication and communicated well with parents:

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> *'At school there's a nurse and I find school very helpful with him, they keep an eye on it, they're very aware of it. You know, there's obviously several other children with inhalers and they're very up to date, give it back to you if its out of date, they listen to him if he asks for it, there's never a problem like that. I feel he's safe in their hands…I do think the school are quite reassuring, to know that they keep an eye on him for me, even if it was a false alarm, I do think the school are very good.' Parent 2*

Parent 1 seemed less certain about school, this might have been because her girls were in secondary school and perhaps the asthma support was not so evident there:

> *'I don't know of any school nurse really. I mean, I presume there is one, but I don't think the girls have actually seen her…No, they haven't come back to me and said they'd actually seen her about asthma or anything' Parent 1*

Parent 4 was clearly less than satisfied with the school management:

> 'How have the school communicated with you?
>
> *Quite poorly actually….so then I've given him his inhaler, which is like these two days in April, so I've administered that, and he hasn't felt that he's been able to go and speak to someone about his inhaler……I think what I'm trying to say to you is the communication is lax.*
>
> *I know that the school health advisor, they used to be called the school nurses, that she monitors all the children with asthma in the school, but I completed a form when xx started reception class and I haven't done anything else since. So the school health advisor hasn't followed that up with me…' Parent 4*

So it appears that the school asthma policy is more evident in some schools than others and that some parents are more aware of it than others. Whilst only one of the four parents seemed actively unhappy with the school management of asthma, she was also aware that there were school based services and she had previously referred to the asthma nurse insisting that her son keep an inhaler in school suggestive of a relatively close awareness between school and the NHS of her son's perceived needs.

Self-care

Parents referred to their own ability and the ability of their children to self-care and manage their asthma:

> *'… they do it mainly themselves now really. You know, they have one spray that they have morning and night and then they've got ventolin for them to take in school, so they know when they need to use it really' Parent 1*

Referring to their own capability and confidence:

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> *'I think I'm quite confident, yes, I mean I know what the triggers are and I know what signs to look out for… if there's something I'm concerned about, I could always go to the internet, like the national asthma campaign or something, and get information from that, yes.' Parent 3*

From these comments it would seem that children are relatively confident about when they need their reliever inhalers and older children are capable of self-managing this. Parents seem knowledgeable and know how to access information, some based on their own experience, others through living with the experience but bearing in mind that all four of these families have some kind of family history of asthma. Support from school or the health service appeared to be there in the background when they needed it but for the most part, on a day-to-day basis, parents and children were able to manage the asthma successfully.

In summary, these four parents of six very different children with asthma appeared to be managing the condition well with varied levels of support from the NHS and school. They also drew on their own knowledge and experience quite considerably to make decisions and manage treatment. A striking feature of the interviews was the degree to which parents referred to the inhalers or sprays, their focus apparently almost entirely on medical management of asthma. When prompted, they were able to discuss triggers but in other stages of the interview kept coming back to the inhaler. This suggests that whilst the parents did seem fairly confident in their ability to manage asthma this did rely quite heavily on a medicalised approach. However, none of the parents referred to recent or frequent hospital admissions suggesting that in the main, their childrens' asthma was well controlled. There were only passing references to exercise and no one spoke of using breathing exercises or environmental techniques to manage the asthma. This poses a degree of tension between the public health model of school health that was put in place to support children with asthma in this case study site and the fairly conventional medicalised response that parents have. It is not particularly surprising that parents focus on treatment, asthma can be very serious or even fatal and it is natural for parents to want to be sure that the right medication is being given at the right time. It is perhaps more surprising that there was not a greater awareness of some of the education and awareness raising that has taken place in the schools. Equally, it could be argued that as public health policy the asthma strategy should be operationalised in the background, providing an 'invisible' service between home, school and the NHS.

Children and young people's experience

Data from children and young people in the PCT were obtained through two focus groups (1 with 3 primary school children; 1 with 3 secondary school children) and individual interviews (3 girls; 2 aged 11, 1 aged 13). As with the parent's interviews these were analysed thematically.

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Some aspects of the analysis is more concerned with the childrens' and young peoples' overall experience of asthma than the experience of the asthma being managed within a school health context. However, we made the decision that within a whole systems approach it is not possible to separate out the experience of a condition from the experience of the service, especially for children and young people who are often still dependent on their parents or carers to organise services. Therefore we provide these themes as part of the context in which children and young people experience the public health approach to asthma management.

Consequences of living with asthma

The main negative consequence for everyday life reported by children in both interviews and focus groups were participation in sports, and gym lessons in particular. Doing exercise often made children out of breath or wheezy, and there were often reports that children would have to stop half-way through lessons to use their inhalers or just to sit out and recover. Another consequence was being less 'free'; having to always make sure there's an inhaler around, remembering to bring it with you when out playing.

> *'Before I had asthma I was kinda like free, I could run around and play without having to worry about having to have my inhaler around in my pocket. After, it's kinda hard to join in cause I always felt that I was gonna be embarrassed by having asthma…or having to use my inhaler. Stuff like that' Young Person 1*

Also related to being less free was that many children had their asthma set off by being around furry animals which limited the amount of time they could spend at friend's or relatives' houses. For some it also meant being wary of sleepovers, if asthma was likely to occur at night.

At school

The younger children tended to report relying on a teacher or dinner-lady if they had any trouble with their asthma during school time. Many (all ages) would tell their friends so that they could get the support they needed.

School trips were mentioned as potentially difficult; younger children could generally rely on teachers to ensure they had their inhalers with them while older (secondary school) children felt they needed to take on this responsibility themselves. The older children also felt that teachers were not really aware of which children had asthma, so did not realize there could be a problem.

Form tutors and sports teachers generally knew about children with asthma, and when teachers knew about asthma, they were generally perceived as helpful. Those that do not were perceived as unsympathetic:

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> *'I'd run 1500 metres the other day and just collapsed at the end and it was just like "oh you'll be fine, just get up and carry on" which was like, you know, my God' Young Person 4*

Sometimes teachers made unhelpful suggestions (such as getting a drink of water) when a child got wheezy:

> 'So how do you know that the teachers don't know? Have you had an experience of…having an attack or something? *Yeah, and they just send you out for some water.' Young Person 5*

None of the children knew who the asthma link person in their school was, or even that there was one. Awareness of school nurses varied, but children who had dealt with the school nurse generally reported them being unhelpful but this was unclear if they meant the actual school nurse or first aid person. Most of the children knew about the emergency inhalers kept at their school, and those that had used them were very positive about having this resource at the school. It provided a sense of security, especially for children who had had negative experiences of severe asthma attacks (such that had resulted in having to travel to hospital).

Who to talk to

Most of the children said they would talk to their mum about their asthma if there was anything they were worried about. Many would also talk to their friends, and form teachers if they were at school. A personal relationship (such as with a tutor) appeared more important than expertise (e.g. a school nurse).

Health professionals

Many of the children reported having regular check-ups for their asthma, although most were uncertain of exactly how often this happened. Mostly they reported having to do peak flow (which some felt could be difficult or awkward) and getting prescriptions for inhalers.

> 'What is it you don't like about doing the peak flow? *I just never have. I get embarrassed. I don't like going to the doctor's anyway.* So is that more what it's about, going to the doctor's rather than…? *Yeah. I feel like I'm failing the test or something.' Young Person 3*

Health professionals were generally reported to be helpful and friendly, although some of the older children felt that they were repeatedly being told the same thing over and over.

> *'They ask me the same questions every time. When was my last attack, do I think it's getting worse, do I think it's getting better.*
>
> Do you think that it should be done differently?

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I don't know, I mean, cause I've had it since I was little, they could hardly explain it to me what it was, like what it meant, then. But, I've never really remembered them explaining it since then either. Like, as I've got older, I know I've had leaflets about it and things, when I've been sitting like in the waiting room and what ever. But… I've never had anyone properly explain it to me, which I would prefer now that I'm actually old enough to understand it.' Young Person 6

All the children said that their doctors and nurses would talk to them as well as to their parents, and would explain the procedures and results of tests. The sense of getting health care from a specialist was also important to young people.

'So they're quite good at talking to you and not just your parents?

Yeah. And they're quite friendly as well. So like when you get praised you feel better about yourself and all that.

Yeah?

Yeah. You kinda feel better.

Do you think that's really important that they tell you when you're doing well when you are?

Yeah it is really, cause then you feel more confident and stuff. To do like, stuff like basketball and all that.

Yeah.

Yeah. You know you've got it from a specialist, so you're alright really.' Young Person 1

Family

Many of the children reported having other family members who also had asthma. This meant that those family members would understand what they were going through and could be helpful because of their own personal experience. This was also evident from the parents' data. Parents were often reported to be making sure that children always had their inhalers with them and while some (the older children) found this a bit repetitious, they all appreciated that it was beneficial to them.

'What about your parents? Are they very helpful when you're at home?

Oh yeah, yeah. Cause every time I go to play they're always like "do you have your inhaler?" (laughs), and every time I go out somewhere with my friends like maybe to the town, I'm always checked for my inhaler in my pocket or my bag (laughs). And if it's like running low they take it off me and give me a fresh one.' Young Person 2

This also resonates with the parent's data for whom the necessary medical security of the medication via the inhaler was a repeated theme.

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Friends

The children said that their friends usually knew about their asthma and would be helpful and supportive. Sometimes being different from your friends could be difficult, especially related to PE and sports. It might mean getting picked last for teams, not being able to run as far or fast as your friends, or having to pull out of games early.

> ***'Does it make you feel very different from your friends?***
>
> *Yeah, sometimes, cause when I'm playing and I go "I've got to sit out, I've got to sit out" and they go "oh, that's not fair, we need to .go on playing" and stuff, but I've got to really. (laughs) cause they're so used to be running around constantly and I'm just the one who's in and out sort of thing.*
>
> ***But all your friends know about your asthma and what's going on?***
>
> *Oh yeah. They sort of understand. (laughs)' Young Person 1*

Using inhalers

Children varied in how vigilant they were in always bringing a reliever inhaler with them, depending on the severity of their asthma. The girl who appeared to be most badly affected of all the children interviewed reported always having hers with her, mainly because of a frightening experience when having to travel to hospital by ambulance during a bad attack. Those who had infrequent and mild attacks reported often forgetting or even deliberately leaving their reliever inhaler behind.

> 'You don't have your inhaler at school?
>
> *I do for like sports day and things like that, but in general if I just go to PE lesson I don't bother. It's too much hassle' Young Person 2*

This would appear to be contra to parental expectations and anxieties, but in keeping with 'normal' teenage behaviour.

The younger children sometimes found using the inhaler difficult, saying that it did not fit properly. None of the children reported feeling awkward about having to use their inhalers when out with their friends or at school.

Difficulties and side-effects of using inhalers included feeling dizzy or coughing if inhaling too deeply, and the taste of the inhaler.

> *'Sometimes when I take my brown inhaler it makes me cough more cause it hits the back of my throat and that makes me cough more…sometimes I'm scared to take my brown one in case it makes me cough even more, and then I take my blue one. Cause that one doesn't affect me as much as the brown one.' Young Person 4*

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A couple of the children indicated that they were wary of using their inhalers too much, either because their parents had warned them from using it unnecessarily or because they themselves were worried about the effects the inhaler might have on their body.

Self-help

In addition to using the inhaler, some of the children had developed techniques that they found helpful in the controlling their asthma. This ranged from having a drink, playing an instrument, or using relaxation techniques.

> *'I'll just stop and just won't do anything for a bit. Sit down. My teachers, the couple of teachers that it happens with they know, I've explained it to them before…so they're alright with it… It doesn't work at home, but it works at school.' Young Person 2*

These techniques were of interest in terms of the education and awareness of asthma in schools. Parents had not talked about such techniques, suggesting that perhaps as the girl above indicates these are more techniques to be used in the school environment.

Asthma changing over time

Most of the children, especially the older ones, said that their asthma had improved as they got older. Most also reported feeling more confident in how to deal with their asthma, partly because they were more able to handle it themselves without having to rely on the knowledge of parents or others, and less worried about it than they had used to be.

> *'Don't know, it's just, it's not as bad anymore. Just got better as I've got older. It's got easier. Plus, I don't really care about it as much anymore. Whereas before it used to be going "oh God", I just didn't like it. It doesn't bother me anymore.' Young Person 2*

Improving support

The area that children were most likely to suggest need for change was for greater awareness among teachers other than form tutors and PE teachers about asthmatic children in each school. In terms of help provided from health care professionals, views were generally positive.

> 'Is there anything that you think could be made better, that could help you even more in dealing with your asthma?

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…making sure that every school has, or every like the nurse in the area, most of the time, knowing about asthma, and making sure all the teachers know about it as well, so they don't kinda huff and puff when you have to go outside and take it…' Young Person 1

Summary

This was a relatively small sample of young people, which nonetheless provided some insights into the views and experiences of having asthma in this PCT area. Overall, the young people seemed fairly confident in managing their asthma and felt able to talk to their parents and peers about the condition. There was less evidence that they felt that school was supportive, in fact none of the young people knew who the asthma link person in their school was, or even that there was one. Awareness of school nurses varied, but some reported that specialist help from a nurse or doctor was important to them. A good relationship with a teacher was also seen as important in the school environment.

Most of the children knew about the emergency inhalers kept at their school, and those that had used them were very positive about having this resource at the school. It provided a sense of security, especially for children who had had negative experiences of severe asthma attacks. Overall, young people did portray some anxieties about their asthma but also a sense of confidence and control in coping with it both at school and at home. The inhaler was clearly an important component in the self-management of asthma and, like their parents, young people referred to this a lot.

Whilst it is not appropriate to draw conclusions about the public health model from this small sample of young people in the PCT, it does provide a flavour of their experience alongside the survey data that provide further and wider data on young people with asthma in this context (discussed in 6.1).

5.1.5 The causal system

The causal system can be defined as the cause and effect network of health, education and social care within which children and young people with asthma are living. In this PCT the major networks that were seen to be working towards improvement in asthma management and prevention were the NHS, in the form of the PCT including Public Health, Accident and Emergency and General Practice, and the Education system. The voluntary sector was also involved because a major grant was awarded by Asthma UK to coordinate the strategy for the first 12 months. However, as described above the children and young people are also living in an area where air quality is poorer than average. Therefore the nurse-led strategy had to demonstrate its impact and outcomes within this cause and effect network.

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The PCT

As the asthma strategy was emerging and developing the PCT was in a period of reorganisation as was being nationally experienced under the *'Creating a Patient led NHS'* (Department of Health, 2005e) initiative that set out to reduce the overall number of PCTs by half and to increase and improve their commissioning role. The change was systematically criticised for the way that it would de-stabilise PCTs (O'Dowd, 2005). The asthma strategy would be part of the provider function of the PCT whilst Public Health would become part of the commissioning function thus giving rise to potential tension between the commissioning and delivery of the asthma strategy.

Simultaneously General Practice and NHS Hospitals Trusts were undergoing organisational and management changes. For example, the Spending Review of 2004 led to the development of Public Service Agreements (PSAs), which were across all government departments but filtered down from the Department of Health to the NHS. PSA target 13 for example was:

> i. by 2010, 'increase life expectancy at birth in England to 78.6 years for men and to 82.5 years for women'
>
> ii. 'reduce mortality rates from heart disease and stroke and related diseases by at least 40 percent in people under 75'
>
> iii. 'a 40 percent reduction in the inequalities gap (for mortality rates from heart disease, etc) between the fifth of areas with the worst health and deprivation indicators and the population as a whole'
>
> iv. 'reduce mortality rates from cancer by at least 20 percent in people under 75'
>
> v. 'a 6 percent reduction in the inequalities gap (for mortality rates from cancer) between the fifth of areas with the worst health and deprivation indicators and the population as a whole'
>
> vi. 'reduce mortality rates from suicide and undetermined injury by at least 20 percent'
>
> (Source: Statistics Commission, 2006)

NHS organisations were and are under considerable political and financial pressure to achieve these targets and those areas not directly affected (such as asthma) may have been considered less of a priority by some NHS organisations. Similarly, the education system through the Department for Education and Science (DfES) was subject to PSA targets such as PSA Target 6:

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'by 2008, school absence is reduced by 8% compared with 2003'

Although this PSA was not directly health related, by developing ways of managing and supporting children with LTCs such as asthma, schools could possibly make a difference to absenteeism. Indeed, part of the justification for the asthma strategy in this PCT was to reduce school absenteeism.

However, at around the same time the National Service Framework (NSF) for Children and Maternity Services (Department of Health, 2004d) did provide an exemplar pathway for asthma in childhood that provided impetus for NHS providers of asthma care for children, in partnership with schools and other agencies. The NSF therefore could be seen as an enabling factor in the development of the asthma strategy in this PCT.

General Practice

General Practice was also implementing QOF as part of the contract for GMS, which attracted payment for QOF points awarded at different indicator levels and accounts for approximately 25 percent of practice income. Thus, for asthma, QOF points could be awarded for keeping an asthma register through to monitoring those diagnosed with asthma having annual asthma reviews. This clearly provided an incentive for GPs to be concerned with asthma but the QOF indicators were not specific to childhood asthma although they included them.

Practice nurses have long been seen as well placed to manage asthma in general practice (Charlton *et al,* 1990; Jones *et al,* 1995; Griffiths *et al,* 2004). However, as shown in the literature review (section 3), the evidence for effectiveness is scanty and there are no systematic reviews that specifically address practice nurses and even fewer studies that address childhood asthma in primary care. Nonetheless, there has been a large increase in practice nurses since the 1990 General Practice contract was introduced presumably on the basis that they can provide a more efficient service that meets patient needs. Current evidence suggests that, under the new contract for General Practice much of the work is undertaken by practice nurses (McDonald *et al*, 2007; National Audit Office, 2008).

Whilst general practice is seen by patients (in this case both young people and their parents) as somewhere where they can seek expertise for their asthma, there was little reference to it other than for annual reviews and inhaler prescriptions. As part of the wider asthma awareness strategy the asthma coordinator was keen to involve general practice and to train as many practice nurses as possible, but it was apparent that there were some obstacles to this being achieved. It can be speculated that within the GP contract it is sufficient to register and monitor asthma patients but not necessary to provide a personalised management programme for

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childhood asthma and that therefore practice nurse training in this area may not be a priority.

The Education System

All schools and NHS organisations are mandated to operate within *t*he *Every Child Matters (ECM) (*Department for Education and Skills (DfES)*,* 2004) policy framework, which provides the main guiding agenda for outcomes for children and young people in the UK. *ECM* represents a significant development in policy responses to children and young people, in that it combines health, social and educational objectives, thereby attempting to create a seamless policy response across the multiple contexts and environments of the child. One of the key principles underpinning current UK services and policy is that of the reconfiguration of services around the child and family. *ECM* specifies 5 core outcomes for children and young people:

i. Being healthy

ii. Staying safe

iii. Enjoying and achieving

iv. Making a positive contribution

v. Achieving economic well-being

A coherent asthma policy as enacted in this PCT clearly provides a direct response to the *ECM* health outcome. In addition effective management of asthma for children enables young people with such LTCs to enjoy school and make a positive contribution. Specific guidance has also been issued jointly from the Department of Children, Schools and Families in relation to children with asthma to all local authorities and all schools and early years settings and their employers (Department for Education and Skills and Department of Health, 2005, updated November 2007). The policy implemented within this PCT enables adherence to the key components of the medicines management policy for example:

1. *Children with asthma need to have immediate access to their reliever inhalers when they need them.*

2. *Children who are able to use their inhalers themselves should be allowed to carry them with them.*

3. *All schools and settings should have an asthma policy that is an integral part of the whole school or setting policy on medicines and medical needs. The school environment should be asthma friendly, by removing as many potential triggers for children with asthma as possible.*

4. *All staff, particularly sports teachers, should have training or be provided with information about asthma once a year. This should*

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> *support them to feel confident about recognising worsening symptoms of asthma, knowing about asthma medicines and their delivery and what to do if a child has an asthma attack.*

Thus, as has been noted in the earlier section on context, the experience of these children and their parents, along with the health practitioners, was being considered during a period when schools were embedding *Every Child Matters* (Department for Education and Science, 2005) as well as the *National Healthy Schools Standard (*Health Development Agency, 1999*)* into the education system. Almost all schools in the PCT area had achieved the National Healthy Schools Standard and the Asthma Friendly School status was seen as an additional standard to be achieved. By early 2008 about 50% (55) of all schools in the PCT had achieved Asthma Friendly status. This includes staff training in asthma, visibility and accessibility of inhalers, children independently managing their own inhalers, trigger avoidance (e.g. appropriate animals in the classroom). The limited evidence available on the effectiveness of other asthma management schemes led by school nurses (Salisbury, 2002b) would suggest that there is some marginal benefit in developing school nurse-led programmes.

The Healthy Schools website quotes:

> *'Offering close support and guidance to primary care trusts, local authorities and their schools, we're equipping children and young people with the skills and knowledge to make informed health and life choices and to reach their full potential.*
>
> *More than 97% of schools nationally are now involved in the programme and over 70% of schools have achieved National Healthy School Status. This translates to around 4 million children and young people currently enjoying the benefits of attending a Healthy School.'*
>
> *Healthy Schools, www.healthyschools.gov.uk, accessed 03/04/09*

Schools themselves have to demonstrate through their audits and reports how they are contributing to the four key themes of the whole school approach to becoming a healthy school. The themes are personal, social, health and economic education, healthy eating, physical activity and emotional health and well being including bullying. These are very broad themes that can relate to many aspects of the curriculum and pastoral care within a school. Governing bodies have to manage these important aspects of the school alongside the priorities and targets that are set by government for teaching and learning, achievement at all key stages, absenteeism, behaviour and financial management. It is perhaps not surprising if asthma awareness is not a main priority for most schools and yet in this PCT the asthma awareness strategy has been implemented

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across 55 percent of schools suggesting that the strategy has penetrated into the education system. The fact that the young people do not seem overtly aware of this is also not surprising given the other priorities but it also suggests that more could be done to ensure that the education system and health care system communicate more closely. However, an alternative view on this is that since hospital admissions for asthma have reduced substantially in this PCT and since the young people in our survey have modest levels of breathlessness and relatively good health indicators, then the public health model is effective at the population level in a 'seamless' way that is not overtly apparent to the service users. The evidence for this remains inconclusive.

5.1.6 The data system

The data system is well developed in relation to the audit of emergency inhaler use, hospital admissions and mortality. These data can be communicated across the PCT and between schools and GP practices. However, as indicated above, GP data from the QOF, although freely available, are not specific to children, and therefore it is challenging to use these data as a method of identifying any changes in quality outcomes for these children.

However, at a local level, the school health advisor and the school nurses spoke positively and creatively about the way in which data were managed and communicated to provide information systems across the health-education organisational spectrum and between health professionals, parents and young people. The school nurses referred to the system they have implemented to create an asthma register of school-aged children that will enable them to have a record of who the children are:

> *'But when we've been into schools and we actually say you know the importance of this because there are so many children with asthma. And usually you'll get one on board that can hand out the forms to new children coming into school. So it's not sort of just done on an annual basis. Any new children coming into school now, the parents will be sent the asthma information form and hopefully they'll be put on the register. But it's really keeping a watchful eye.'* School Health Adviser 2

The asthma register was an important tool in the day-to-day implementation of the strategy as it enabled the asthma coordinator and her team to both collect data on the progress and reviews of these children and to manage the audit of the emergency inhaler use.

They also referred to the way in which they used a data system of their own creation to communicate with primary care, in particular with practice nurses:

> *'I think one of the main issues was obviously parents not taking children to their follow-up, you know to the asthma clinics, that*

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> *was a big problem and we were actually saying well maybe we could be seeing the children and the parents at school, is that something that, as school health advisers, is there a problem why they can't take them to their asthma clinic, could we follow those children up? Or at least make contact with the parents so that you know, so how it or what it is for them you know to go along to their asthma clinics at the surgery so… And the GP that was there at the time so they thought that was an excellent idea. But we have a wonderful form as well, liaison form. So any of these children that are causing us concern, you know we can actually do a referral with parent's consent obviously, to the asthma nurse, the practice nurse.'* So you can refer them directly back… *To the GP if they need to but we tend to be guiding them more to the practice nurses hopefully (laughs) and then if they feel it necessary obviously the GP. And vice versa, I mean, the asthma nurse at the surgery, could do a referral to us although I've not personally sort of received many of those, asking us to chase up children. But I've done several referrals through to various practices because of those children that we're picking up with the persistent night coughs you know, or wheezy and breathless after exercise, yeah….' School Health Adviser 2*

Here, the school health advisor is referring to a system that evidently works in one direction – from the school health advisor to the practice nurse or GP but she has no experience of this operating in the other direction, suggesting that whilst primary care are happy to receive referrals they either do not refer cases back to the school health advisors or they do not make use of the liaison form system. This could have implications for the individual children with asthma in that their support and treatment may not be managed seamlessly and also at the population level where the parent/child population may not be aware that there is a system in place for their GP or practice nurse to liaise with the school health service. Indeed, it did appear that primary care was the weakest link in this data system:

> *'It's very difficult to communicate with GP's isn't it you know, because we're not just actually covering the schools in a certain catchment GP area. Whereas the health visitor would be working with a particular GP and could do that liaison so much better, we're dealing with so many GP's you know, children are coming from all over the borough to certain schools and that is a problem sometimes. It's how can you make that contact and at the moment the only way we've got is either by phoning the practice nurse or the actual referral forms that we have. So it is difficult, more difficult for us.' School Health adviser 3*

However, despite some of the apparent difficulties in the existing system for generating and managing the data about childhood asthma locally, the asthma coordinator described ambitious plans for creating an on-line system that would enable parents, schools, hospitals and primary care to access data and information:

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'So what we're actually hoping to achieve at the end of this is some sort of framework, integrated care pathway, I'm not really sure what it will be called. Some sort of framework which has basically got the child or young person and their family at the very heart of the document, really in the centre of it all. Very much following the asthma exemplar in the NHS really but almost localising it, what's available here so it will include guidelines, protocols, referral pathways, points of contact, sign posting, so if you are, I don't know, a teacher and there's a child with asthma in your class who seems to suffer with symptoms more so when they do PE outside in the summer, that teacher can access the information that they need …so it will available on the PCT intranet site, the hospital's intranet site, the local authority's intranet site. It will be available externally as well on the internet. It will be available in hard copy for the dinosaurs out there but by, you know clicking on links it takes you to where you want to go but it's relevant, it's local, it's updatable so you know, the correct telephone numbers, the correct points of contact, the correct website addresses are there.' Asthma Coordinator

Thus while the data systems for this model were not perfect, there were new ways of developing information across the PCT and schools the whole time. The asthma coordinator was seen as the champion of much of this work as clearly identified above. The weakness of this part of the system was the inter-dependence it therefore had with the asthma coordinator's enthusiasm and leadership style. The anxiety about this model that was raised on several occasions was how it would be sustained if the coordinator was no longer in place.

5.1.7 The organisational whole system

The organisational whole system has already been identified as one that, in this case study site, is reasonably well integrated, at least between health and education. In this case study this could more accurately be described as the health and education network within which children and young people are recognised through the health navigation (Brooks and Kendall *et al,* 2007) approach to the organisation of asthma management. Thus, as discussed above, the coordinator and the team of school health advisors enable the child and family to navigate their way through the health and education network so that the asthma can be efficiently and appropriately managed seamlessly between home, school and the NHS.

Practitioners

Practitioners are organised as described above in a hierarchy that reflects the strategic leadership of the coordinator, the school asthma advisors and the asthma support workers.

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This model is highly dependent on the coordinator in terms of leadership, expertise and her ability to envision projects such as the asthma awareness packs and to campaign for necessary policy such as the emergency inhalers. The coordinator was frequently referred to throughout the interviews as the lynch pin of the service. The weakness of this model therefore lies in its dependence on a key individual with little evidence of succession planning or future reconfiguration of the model to a more flattened hierarchy.

Practitioners identified strong benefits from being able to access and work with the specialist asthma coordinator. Benefits were felt in terms of clear strategic leadership relating to policy and practice concerning the management of asthma in young people. The ability to access specialist knowledge was also felt to improve the practice of more generic community practitioners.

The local health organisation

As described, the model has been adopted across the PCT and is therefore a whole organisation public health model for asthma. Whilst all the PCT schools are involved in the strategy, the coordinator was also very concerned to include all GP practices and practice nurses as well as all other parts of the organisational system:

> *'Yeah we've just set up the Paediatric Respiratory Forum and what that has done has bought together a range of professionals from primary and secondary care, community services, education, safeguarding children, which is another big area. Brought all of these people together and asked them to look at children with asthma in [the PCT], what we can do about it and how we can bring it all together basically. We had a first workshop and we got an awful lot of feedback from that and as a result of that we're actually setting up various different working groups in each of the areas. So primary care, A&E, the children's ward at the hospital, safeguarding children team, education as in, not education and training, but as in children's education.' Asthma coordinator*

This PCT has been recognised by Asthma UK (2007) as one of the leading organisations for reducing hospital admissions for childhood asthma. For example, children's emergency admissions in this PCT, an area with a serious shortage of GPs, are 49 compared to the standardised national average in England of 100 (rate of hospital admissions per head of population, standardised to account for regional differences in age and sex, with the average for England assigned a rate of 100). The PCT has been working with Asthma UK to help prevent unnecessary admissions by introducing a programme of training for local health professionals and

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recruiting a dedicated asthma nurse to raise standards of asthma care and understanding in local schools.

5.1.8 Conclusion

What can be concluded from the analysis thus far about the nursing contribution to the public health model of asthma management among the school age population?

Firstly, the user experience from the perspective of both parent and child appears to be that whilst they are not overtly aware of the school asthma strategy, they have access to a well organised and coordinated service that in its delivery is doing its best to cross health and education sectors. This in turn has led to the provision of a service that whilst not overtly visible to children and parents, has led to an improvement in the awareness and education about asthma in schools (as evidenced by the award of the Asthma Standard to 50 percent of schools in the PCT area and the reduction in hospital admissions).

Secondly, while the causal system is complex and constrained by constant NHS re-organisation and policy development, the organisational system and data systems have served to overcome some of the complexities through the successful implementation of the nurse-led school asthma strategy. There are some weaknesses in these systems, such as the need to improve communication with primary care and the apparent lack of succession planning for the asthma coordinator and yet there is creativity and a real sense of purpose within the school nursing team that provides optimism that such barriers can be overcome.

Thirdly, the leadership provided by the asthma coordinator is both a major enabling factor and also a potential barrier to the whole system. Clearly, the asthma coordinator has provided the nursing team as well as the wider organisational components with a vision for asthma management in school-aged children. This vision has led to the implementation of the school asthma strategy, and the ensuing impacts including growing awareness, prevention of hospital admissions, confidence in schools about asthma management and healthier children. But, as indicated previously, the dependence on one person to drive a strategy without forward planning for how it will be sustained if she were not able to continue for any reason could have serious implications across the whole system, leading eventually to system failure.

5.2 Primary Care Nursing Model

Two case study sites provided the data for this model. Both were based within GP practices in primary care. The model in case study site PCN1 is a

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nurse run service for patients with type 2 diabetes based in a GP practice in Wales. The model in case study site PCN2 is a nurse run, primary care CDM model which uses clinics based in a GP practice situated in the East Midlands.

Over the past two decades there has been an increasing shift from secondary to primary care, with traditional professional boundaries being challenged by health policy directed at role expansion or new role development (Whyte, 1996). In addition, successive GP contracts have challenged current ways of working and initiated expanded roles for nurses working in general practice. The 1990 GP contract emphasised the importance of health promotion activities which became a role embraced by general practice nurses (GPN) (Broadbent, 1998). The NHS Plan highlighted the promise of extended nurses' roles (Department of Health, 2000a). However, while the first National Service Framework for coronary heart disease (Department of Health, 2000b) identified the role of GPNs in running nurse-led clinics, there was a focus on nurse specialists rather than GPNs in the NSF for diabetes (Department of Health, 2001a). The new GMS contract of 2004 outlined a payment structure linked to a Quality Outcome Framework, and for practices to be able to reach their QOF targets there was a need for GPNs to take on much of the primary care work around chronic disease. The nurse's increasing role in primary care was recognised and 10 key roles outlined including delivering NSFs and undertaking work previously done by GPs (Department of Health, 2005d). The contribution of GPNs to CDM was further recognised in more recent reports on diabetes care (Department of Health, 2007c), and greater opportunities and incentives for GPNs to advise people how to improve their health in order to prevent chronic disease are promised within the Darzi Report (Department of Health, 2008a). It is likely that the significant role of GPNs within CDM will be further highlighted within the imminent NSF for COPD.

5.2.1 The PCN1 Case Study Site

The PCN1 case study site is a nurse run service for patients with type 2 diabetes and is based in a GP Practice with practice population of 6,500 in a Local Health Board (LHB) of 91,000 (mid year 2006). A practice nurse runs a weekly diabetes clinic (eight hours), thereby managing the care of the majority of the 312 patients with type 2 diabetes registered at the practice, 80 to 90 percent of whom do not see the GP about their diabetes. However this number may include a handful who receives all their care from secondary care. There is 5.4 percent prevalence of diabetes in the practice population (compared with 3.4 percent for Wales).

Nurse diabetes clinics began at this practice in the early 1990s, when the GPs wished patients with diabetes to be treated locally and in a more structured way in primary care, rather than travelling to secondary care, where there were long waiting times. It was not initially intended to be a nurse run service: the practice nurse administered relevant tests and measurements prior to the patient seeing the GP.

"The GP that was there at the time, he wanted to you know, provide a service for patients with diabetes in primary care. Most of it was secondary care-based and you know, when we discussed it, we felt that there was no real need for the majority of patients with diabetes to have secondary care." PCN1 Practice nurse

Over time, with the development of the skills and confidence of the current post-holder, a nurse run service has developed: GPs and secondary care are now much less involved.

The GP practice is located in a LHB with a projected population increase of 2.4 percent by 2016 compared to 7.8 percent for England. One third of the wards (and almost one third of the population) are in the most deprived fifth of wards in Wales.

Table 8 shows there is a much lower proportion of ethnic minorities in the LHB than in Wales and England. The population density is higher but the there is a mixture of urban and rural with built up areas only accounting for 20 percent of the LHB.

Table 8. Demographics of LHB

LHB		Wales	England
% ethnic minorities in population	< 1 %	2%	9.1%
Population density (people per hectare)	7.2	1.4	3.8
% people of working age in employment	67%	71.5%	75%

Office for National Statistics, 2004a; Office for National Statistics, 2004b; Office for National Statistics, 2008)

Life expectancy and the age standardised mortality rate are generally similar to Wales but the latter varies across the area. There are high rates of smoking and low rates of healthy eating and physical activity in the LHB. These contribute to a high incidence of conditions such as cardiovascular disease, cancer, strokes, high BP, diabetes and obesity with 56 percent of adults overweight or obese and increasing. Twenty-five per cent of the population have a limiting long term illness. The age standardised population of adults who reported meeting the target for healthy physical activity in the LHB is lower than the Welsh average and 7th lowest of the 22 LHBs.

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5.2.2 The PCN2 Case Study Site

The PCN2 site is nurse run, primary care CDM clinics based in a GP practice serving 8,500 people in the East Midlands. The nursing team comprises of three qualified nurses (one nurse practitioner and two practice nurses) and one health care assistant (HCA). The nurses manage four chronic conditions; chronic obstructive pulmonary disease (COPD) and asthma which have discrete clinics led by the nurse practitioner, coronary heart disease (CHD) which has a discrete clinic led by one of the practice nurses, and diabetes which is managed in generic clinics covered by any of the nurses. There are approximately 300 asthma patients, 180 COPD, 200 type 2 diabetes and 50 type 1 diabetes and 300 with heart disease. There are thousands who are hypertensive, many with other diagnoses. Patients are able to access the generic clinics with any condition if it is more convenient. Patients are contacted annually by the practice and asked to make an appointment first with the phlebotomist (if blood tests are required) and then a week to a fortnight later at one of the clinics. If the patient needs closer monitoring this is discussed at the clinic visit and patients are asked to arrange more frequent follow up visits.

The origins of this model have concurrent political and evolutionary roots. The nursing team have been in post for many years (nurse practitioner 16 years, practice nurses 18 and eight years respectively), and with developments in their training their roles have gradually developed in CDM from general health promotion to developing specific skills such as diabetic foot checks, and most recently autonomous prescribing. The nursing team have had a desire to expand their role and have been able to do so within the parameters of evidence based practice and strict protocols. In tandem there have been a number of political drivers with the advent of the GP contract and the need for accurate data a strong influence. The first clinic was set up 15 years ago for asthma but NSFs and QOFs have triggered clinics for hypertension, CHD, diabetes, COPD and epilepsy, with a reported need to protect GPs' time in managing all these chronic diseases.

> *I think it was generated partly out of a desire to extend the nursing role. To initially answer some of the things that were coming out of National Service Frameworks and trying to set up better clinics while protecting doctor time to deal with those sort of problems. Then eventually, yes, QOF came along so they had to be developed further. But yes, I think really initially it was to try and take, well to try and absorb the work that was necessary but also protecting, as I say, doctor time, doctor consulting time.*
>
> *And that kind of - our nurses were there and we felt well okay if we can start to train them up to do some of this chronic work, it's a way of getting through the workload and using their skills that were very suitable for managing that type of problem in general practice.*
>
> *PCN2 GP 1*

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The clinics were set up before the advent of QOF and the nurses do not feel the framework has changed the way the clinics are run apart from ensuring 'boxes are ticked'. However, the NSF for CHD was seen as particularly influential and in the early days the practice would shut down for half a day for educational sessions on CHD management, other NSFs appeared to have less influence.

The clinics have developed with systematic recall systems and the allocation of chronic disease registries to a particular member of the practice staff (dispenser). Over the years patients have become accustomed to the system and 'Do Not Attend' (DNA) patients are increasingly rare although those that do fail to attend tend to be people with asthma who reportedly do not see the need for reviews beyond being prescribed their inhalers.

In addition to NSFs and the QOF, the development of the nurse run clinics have also been influenced by local guidelines such as that of the PCT on prescribing practices, NICE guidelines and gold standards.

The GP practice is located in a local authority district which has a highly urbanised population with population density more than 5 times that for England and a much lower proportion of ethnic minorities (Table 9). Diabetes prevalence rates for type 1 and 2, diagnosed and undiagnosed, for the district are similar to those for England by age.

Table 9. Demographics of LA

LA		England
% ethnic minorities in population	4.5 %	9.1%
Population density (people per hectare)	21.3 3.8	
% people of working age in employment	76% 75%	

(East Midlands Public Health Observatory, 2007; Office for National Statistics, 2008)

Life expectancy rates are similar to those for England and the CHD mortality rate in the LA is lower than both the England and county average. However one of the wards covered by the practice is one of the 20 percent most deprived wards in the county and has a death rate from

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cardiovascular disease, for those aged under 75, significantly worse than the county, East Midlands and England averages. Age standardised mortality rate for respiratory diseases, male all ages, is 130.3 for the local authority, and 69.57 for females. (100 is the SMR for England and Wales) (Association of Public Health Authorities, 2008; Public Health Report on Coronary Heart Disease[6], 2007; Office for National Statistics, 2004).

5.2.3 The Service User Experience

A total of 17 patients were interviewed in the PCN1 case study site. All of the patients were diabetic, seven had type 1 diabetes and were under the care of the local hospital. In PCN1 all of the patients who were attending the diabetic clinic at the GP surgery knew the name of the diabetes specialist nurse (DSN) and saw the same nurse each time they went.

> *'You know I get regularly checked with our practice nurse and she's brilliant, so you've got your feet, you've got everything, your weight.'* PCN1 Patient 8F

Patients with type 2 diabetes attending the GP practice were seen 6 monthly. If patients needed more frequent monitoring this would be discussed and arranged by the practice nurse. The appointments are initiated by the practice, with the patient attending the surgery a week to ten days before the clinic appointment to have blood taken so the results would be available at their meeting with the nurse. The nurse weighed them and took their BP and was able to spend time talking through the results of the monitoring with the patient, providing information and answering patient questions.

> *'She'll say "your weight's going up, do you want back down again" or "you're going down nicely now" and she'll say "your readings pretty good" as a rule. It has been good as a rule.' PCN1 Patient 8M*

Patients often asked about information they had picked up elsewhere, from diabetic magazines, from friends and relatives or from the internet.

> *'If I want anything, if I want some knowledge about something, perhaps I've seen something in the newspaper I will ask her and if she's got knowledge of it, she'll hand it over.' PCN1 patient 11M*

There was evidence of close cooperation between the nurse and the GP. If the nurse thought the patient's medication needed changing she would either organise for this to happen or refer the patient back to the GP.

[6] The full reference has not been given as this would identify the case study site location.

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…'the diabetic (practice) nurse… she's sort of recommended perhaps that I go onto a higher level of pill control for my BP and that. So she's recommended that and then that's been sort of sanctioned by the doctor really I suppose afterwards. Yeah I mean she provides most of the information that I need.' PCN1 Patient 10M

… she'll [Practice Nurse] ask you about all your other symptoms as well as your diabetes, as well as your blood?

'Yes and then she says "I think you need to see the doctor" about something, she phones in to the doctor and you go in and see the doctor then. It's the same with asthma nurse, last time I went to the asthma nurse she decided I needed different so she said I'll make an appointment and I went straight into the doctor.' PCN1 Patient 1F

Patients who were newly diagnosed with type 2 diabetes or who moved into the area with the diagnosis described quite intensive support and monitoring from the specialist practice nurse until their condition stabilised or the patient expressed confidence in managing the condition.

So the first time you went to see her [nurse], what sort of information were you given for example?

'She told me what was going to happen, that you know I would need to read everything, watch labels and she gave us… I think it was a booklet we had and she told me that I would have to have my blood tested…..then she explained the problems that diabetes can cause if you don't adhere to the diet or if you're on the pill. She was very good because she didn't paint it whiter than white, she told us what could happen, you know you can have problems with your toes, you can have problems with your feet, it can be a very bad thing if you were not aware but on the other hand you can live with it if you follow the rules and so where I was initially umm, you know oh it's not so bad, I can cope with it. So she painted both sides of the picture for us and she told me what would happen and could happen but she also told me it didn't need to happen and then she told us that you know we would be… I would have a review twice a year and that has happened where I would be checked over, my weight, my blood, cholesterol, feet and that's happened, it's been good, she's been very good.' PCN1 Patient 8F

Newly diagnosed patients also received input from a dietician and podiatrist who also visited the surgery on a weekly basis.

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So you went with him for his first appointment to the nurse..,.

Patients' wife: *'Yes to the dietician, because she explained everything to us and she asked me what we were eating and to cut out certain things and with cholesterol as well.' PCN1 Patient 8M*

This patient has also been referred to a four week educational course for patients with diabetes and is on the waiting list to do the course. However, patients' experience of referral for educational programmes varied. PCN1 Patient 4M and patient 10M had never seen a dietician. PCN1 Patient 10M had been unable to access the educational course despite four referrals by the nurse. Similarly patient 7M wanted to be able to attend an educational programme

'… if it was a couple of days, where its all you talk about is the diabetes, instead of picking up bits and pieces here, there and everywhere. I think, to me, that could save the health service a lot of money in the long run, if people really knew about the problem, the diabetes that they're actually suffering from.' PCN1 Patient 7M

There was some evidence of fragmentation between the practitioners looking after the diabetic patients at the surgery.

'And I don't, I'm not quite sure how close a team they are for care of diabetics. The doctor, the nurse, the chiropodist, the dietician, it appears to me that they're all working independently.' PCN1 Patient 4M

However, the fact that the diabetic specialist practice nurse only attended the surgery once a week limited patient access and meant that if problems cropped up on days when she was not there the patient would see the GP. Although most of the patients knew the days that the nurse was at the practice and would phone her on those days if they had a problem that was not urgent such as how to manage their diabetes when on holiday in a hot climate and a different diet.

'but that nurse is brilliant, but she only ever works one day a week, which I think is absolutely ridiculous, you know. And I did ask receptionist, can you get in touch with her, but you can't really, you've got to ring and if she's there, only there on Thursday, if she's there and hasn't got a patient then you can talk to her. But if she's got a patient you can't.' PCN1 Patient 4M

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The part-time provision limited access to the practice nurse specialist with most patients saying they would make an appointment with their GP if they had any concerns about their diabetes between their clinic appointments with the nurse, if the GP thought it appropriate he would then refer back to the nurse and an other appointment would be made for the patient at the clinic. If the nurse is unable to attend the clinic is cancelled.

Nine of the type 2 diabetic patients also suffered from a range of other conditions including: coronary heart disease, asthma, lupus, joint problems, increased cholesterol, arthritis, hypertension, angina, enlarged prostate, underactive thyroid, vertigo, triple bypass surgery, stroke, fainting attacks, cataracts, over active thyroid, prostate cancer, hypertension, angina, claudication, faecal indcontinence following radiotherapy treatment. For some of these patients their diabetes was not their main concern and was not impacting on their lifestyle as much as some of their other health problems.

> *'…Oh my arthritis really is my main concern because as I say I'm restricted to what I can do…….But the diabetes, as I say I can manage that, I'm managing that at the moment.' PCN1 Patient 5F*

PCN1 Patient 5M lived in a rural area of Wales and used a subsidiary surgery held in his local village. He had to travel to the main surgery six miles away to attend the diabetic clinic. He also had angina and an enlarged prostate. He felt that his six monthly checks should cover all his diagnosis given the distance he had to travel to get there.

> *'Because I'm looking for them to check me out for diabetes, for angina and for the prostate, I sometimes find that they're quite happy to push the cholesterol business and the prostate business to one side and they're not concerned. I don't want that, if I'm going to go and have a check-up, I want them to check me for every concern that I have, do you understand me?' PCN1 Patient.5M*

Similarly some patients found the focus on the diabetes did not take account of the patient experience of managing multiple conditions. As patient 6M commented:

> *'I already said, I can't do the exercise you know, just a catch twenty-two position, I mean the doctor said to me, "So we've got to keep, watch your weight because it'll affect the diabetes," but what they don't seem to understand is that if you, if you've got the claudication*

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you can't do exercises anyway which means you'll have a hell of a job to reduce weight if you don't do exercises.' PCN1 Patient 6M

In case study site PCN1 conditions other than diabetes were managed by the GP.

'… every time I go and see the doctor, he very seldom mentions to me the diabetes. Obviously because there is no problem with it, but he does... he is always concerned about the BP.' PCN1 Patient 4M

There was also some evidence that GPs were managing the conditions which were either difficult to diagnose or which gave rise to symptoms that were not always responsive to medical intervention. For instance PCN1 Patient 1F believed she had some form of 'lupus' diagnosed in the US but not recognised in the UK. This was causing her a lot of concern and was being managed by her GP and the local hospital:

'…but I have the same tablets as the lupus people have for the burning of the skin sometimes people who used to sit by me would say "oh you're on fire" and it used to make me ill but now they've got that under control I went to see the neuro surgeon and he said that "he just don't know what's happening" he said, "there's something definitely wrong but we can't put our finger on it.' PCN1 Patient 1F

Patients with type 1 diabetes were managed by the local hospital and were more familiar with the concept of an annual review. In some cases the only contact the type 1 patients had with a DSN was at their annual review at the hospital. Other than that they had no access to nursing care.

(You see the nurse) Once a year. So routinely then it's for you then to ask for help, the help that you need i.e. you don't have regular appointments with the nurse.

'No with the Diabetic Nurse, no.' PCN1 Patient 2F

This patient used to attend a diabetic drop-in centre run by the health authority which she found very helpful but which has since closed down. Other patients had much greater access to a DSN at the hospital and were able to phone up or drop in if they needed help or advice.

'I'm familiar with the diabetes, what do they call it? The diabetes centre at the hospital and I know that, and in fact I have done this, I, if I've got a problem I can ring them. I've got the telephone number

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of the diabetes nurse specialist at the hospital so I can ring direct to their office. And on occasions I have, well I have gone.' PCN1 Patient 3F

For type 1 diabetic patients the care of their diabetes was managed exclusively by the hospital with little or no input from primary care.

So you don't see the Diabetes (practice) Nurse attached to the practice …

'I don't, well because I… no one's offered, no-one's offered it. And I don't have much spare time. If I go to [GP] clinic I need to take a day off work ….And I don't find it that easy to attend the GP's surgery….. I don't think that I've felt I needed to go and see a GP. I mean I've been to the GP for other things and they know I'm diabetic so you know, they take that into account when they're diagnosing or treating me. But I don't think I've had anything where I've felt I need to go and see somebody about my diabetes.' PCN1 Patient 3F

Two patients PCN1 Patient 2M and PC N1 Patient 6M have annual reviews at the GP practice. PCN1 Patient 2M had his annual review at the GP practice and then he was referred back to the clinic at the hospital for further treatment. He felt he was:

'…under control of four people if you like, my GP, my practice nurse, specialist diabetic nurse, and the specialist diabetic doctor. So I get controlled by four people and what I'm advised to do.' PCN1 Patient 2M

He found that the hospital nurse was more accessible as she was fulltime whereas the practice nurse was only at the surgery one day a week. Similarly PCN1 Patient 6M uses either the hospital clinic or the GP clinic depending on availability. In some cases the split between hospital and primary care caused confusion for patients who were unsure as to who they should approach if they had a problem with their diabetes.

[if had a problem] I suspect I might head to my GP first but as I say there's such a conflict that I suspect I'd wait for three months until my hospital appointment……..The hospital just don't seem to want to inform the GP what's going on.' PCN1 Patient 7M

There was some evidence that hospital care was replicating some elements of primary care for instance PCN1 Patient 6M received home

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visits from the hospital nurse when he was first diagnosed with diabetes and these continued on a daily basis until he was stabilised.

Patients being treated by the hospital also received access to educational programmes run by the hospital.

The expertise displayed at the hospital led PCN1 Patient 1.3F to view GP practices as less knowledgeable about the disease.

> *'They* [DSN] *helped to run these courses that I mentioned earlier and they do know what they're talking about. And they sound confident and that's because they do know their subject inside out. But that's not, it's not the experience I've had from the GP practices. And I've been to lots,' PCN1 Patient 3F*

Patients also valued the expertise of the medical consultants at the hospital

> … who would you say has been the most helpful to you out of all the professionals that you've seen?
>
> *'I think [Diabetic Consultant G] cause he's got the manner whereby he sits down and he explains to you what he's doing, why he's doing it and if he didn't do it what could happen, he explains it all you know, which is for a person who is going through an illness, I think one of the worst problems is not being spoken to as a layman if you like, [Diabetic Consultant G]'s got that way about him that he can speak to you in terms you understand.' PCN1 Patient 6M*

However, despite this support another patient commented on the need for more information about the blood tests to make the results more meaningful.

> *'If they gave you a little book saying so and so means this and so and so means that. Apparently for diabetes the HbA1C (*glycosylated haemoglobin A1C) *is significant and apparently that's high. My cholesterol was 6, I don't know what 'TRIG' is. HDL cholesterol was 1.49 which I don't know what that is. No I don't know, Urea is 9.8. So they've circled that one and that one which… I don't know whether that means that it's high or not.' PCN1 Patient 2F*

Patients used a range of different sources of support and information, some had relatives who were clinically trained and contacted them, others had relatives who had the same disease and were more experienced at

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managing the condition, they became the main source of information and support.

> *'I could talk to her [nurse] but my step-mother's diabetic, I'm much more likely to talk to my step-mother than I am to seek any help elsewhere. She's the only one really that set me on the right path with my diabetes'…PCN1 Patient 7F*

One particular patient with type 1 diabetes was finding it very difficult to stabilise her condition. Although initially she dismissed the idea of more access to a nurse as she did not feel there was anything more they could do for her clinically, she went on to comment:

> *'I would like to feel that I had more frequent discussions about diabetes with a Diabetes Specialist. And that probably seems like cloud cuckoo land, though I would like that. I would like someone to say "well how's it been this week?' PCN1 Patient 3F*

Thirteen patients and carers were interviewed in the PCN2 case study. Here nurses looked after a variety of different conditions not just diabetes. In each case the patients had attended the clinics run by the nurses at the GP practice on a regular basis. The annual review system set up by the practice to invite patients to their annual check was understood by all the patients and carers interviewed:

> *'It's mainly for all the BP that I go to see xxxx* [Practice Nurse] *and for my yearly… my birthday check-up as they call it'. PCN2 Patient 7M*

If the nurses are concerned about a patient, for instance a raised BP reading they would ask the patient to attend more frequently and to make the appointment. There was evidence that the practice nurses were managing serious chronic conditions such as angina and hypertension.

> *'And apart from seeing the nurses, I mean I've not had to see the specialist* [hospital medical consultant] *again in that time.' PCN2 Patient.1M*

The nurses worked closely with the GPs to manage the patients, often monitoring for side effects of drugs and referring back to or consulting with the GP if problems persisted.

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'But if something crops up that she didn't like she would say make an appointment to see the doctor……., they [practice nurse] kept altering my tablets to try and get my BP down and they couldn't do it. So, at the end of the day they said I think you'd better see Dr E and let him see where you're going with it.' PCN2 Patient 3F

Once at the clinics patients received the results of blood tests and where appropriate their BP and weight were measured and recorded. They were given the opportunity to raise any concerns they might have about their conditions. Nurses reinforced messages about healthy living, eating an appropriate diet and taking regular exercise. Most patients were aware of this and fitted it into their routine where they could.

As well as suffering from one of the specialist conditions targeted by the nurse run clinics (asthma, COPD, CHD, diabetes) all of the 13 patients recruited to the study suffered from one or more additional conditions. The range of additional conditions included: type 1 or type 2 diabetes, angina, hypertension, elevated cholesterol levels, arthritis, on going problems arising from old head, joint or back injuries, splenectomy, cancer, stroke, glaucoma, asthma, COPD, vitamin B12 deficiency, thyroid problems, fibromyalgia, coronary heart disease, aortic aneurism, previous bypass operations, previous myocardial infarctions, obesity, paraneoplastic syndrome, renal failure and falls.

The impact on the patients' health and quality of life, of each diagnosis, varied. In each case there was usually one overriding diagnosis that was causing the patient the most problems, and this was not necessarily the most serious (life shortening) diagnosis experienced by the patient neither did it necessarily coincide with the four clinics organised by the practice nurses.

'So you've got arthritis in your knees, and what other conditions have you got, what's your main condition?

'Well I suppose I've got sugar diabetes, high BP, glaucoma, arthritis, is that the lot? Yeah, I think so….' Which condition concerns you the most? *'The arthritis really.' PCN2 Patient 3F*

In some cases the multiple diagnosis of the patient coincided with the different clinics.

'Is that [diabetes] *your main problem, would you say? Yes, that is my main problem and high BP.' PCN2 Patient 5F*

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Although again patients tended to highlight the impact of one diagnosis over the other:

> But would you say your angina is of more concern to you than your asthma or not?... **'***the asthma is definitely.' PCN2 Patient 1M*

Patient contact with the nurse run clinics varied according to the differing diagnosis. Although most patients could distinguish between the nurses running the clinics and most patients expressed a preference for one nurse or another, very few were able to actually name the nurses or to specify which clinic they needed to attend.

> Do you know her name?
>
> *'I don't, no. And I keep meaning to take her name because I think yes, when I go to see her again I say "you know I want to see that one.' Patient 4M.*

Three of the patients were attending the GP surgery on a regular basis for treatments or monitoring unrelated to the focus of the disease specialist clinics. One patient attended three monthly to receive Vitamin B12 injections (PCN2 Patient 1F). Another patient had started taking fat reducing medication and was weighed monthly (PCN2 patient 1M). A third patient had suffered renal failure following a bypass operation and required close monitoring to prevent further deterioration (PCN2 patient 7M). Regular attendance at the surgery gave rise to a varied experience, in some cases the different checks merged, in others they remained quite separate.

> Patient's wife: *'So it's monthly for your weight and it's six monthly for your BP, your bloods and they check your urine. And then it's yearly you have to go to the hospital to have your eyes done.' PCN2 Patient 1M*

> *'My COPD is only ever checked when it needs to be checked. Even if I go to the COPD nurse for my injection and she has to get my injection and she'll say to me "are you okay". So it's not often my COPD is talked about unless I raise the issue or I'm actually at a COPD appointment.' PCN2 Patient 1F*

There was evidence from the interviews that either the surgery or the patient could initiate an appointment. The surgery organised the annual appointments, patients made more frequent appointments if requested by the practice nurses or occasionally patients would self refer into a clinic or make an appointment to see their GP if they were concerned about any aspect of their illness.

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'He's [son] got one of those machines…. I say "here, can I try" and he tells me exactly what my BP should be and all this, that and the other. If it's high, [BP] I go and see the doctor.' PCN2 Patient 1F

On the whole patients were fairly clear about when to make an appointment with a nurse or when to make an appointment with a GP.

So what sort of thing do you go to your GP for?

'Well this time I went because I had the giddiness and he's sorting it out.'

So would you ever make an appointment to see the nurse or do you always go to the doctor?

'They're good, I mean because I'm on a load of aspirin obviously, I bleed forever and if I cut myself in the day I just phone up and say "I've just managed to cut myself" she [Practice Nurse] *said "can you be here within an hour?" I said "yeah" she said "right, come up" and they sort it out you know.' PCN2 Patient 2M*.

However, access was organised by the surgery making it easier for patients to contact a doctor directly as a result access to nurses was controlled via the appointment system.

'Yes, it's easier for me to see the doctor. The times that I see the asthma nurse and the heart nurse are usually at predetermined appointments, check up appointments as opposed to any other kind of appointment.' PCN2 Patient 1M

There was some evidence that patients made subtle distinctions between the role of the nurse and that of the GP. The nurse was seen as someone who was there to monitor the patients established condition and to offer ongoing support and advice to the patient, someone whom the patient could talk to without needing the justification of a change in prescription or sick note. Nurses would then refer to the GP if changes in medication were required beyond that which the nurse was able to prescribe. Whereas GPs were consulted if something new or different occurred, if the patient experienced new or different symptoms with which they were not familiar.

'… she's [the nurse] *far less intimidating than the doctor. You know I feel that perhaps there are wider boundaries to what you can talk about and discuss and… But her understanding or her willingness to actually come up with a sort of medical diagnosis or to venture into those areas which are quite clearly the doctor's professional concerns, I don't have a problem with the nurse giving me injections, I don't*

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have a problem with her whatever, you know. To some degree it's useful being able to get that lower level of care rather than going to the doctor every time and in some respects her [GP] thinking you want a prescription for something or that you want a sick note.' PCN2 Patient 5M.

The data from patients using services in PCN1 and PCN2 indicate that patients were using the disease management clinics set up by GP practices and found them helpful in monitoring and managing their disease. However, local organisational arrangements restricted open access to these clinics, and in particular to the nurses that ran them, outside clinic hours. More complex cases were escalated to GPs and secondary care. Most of the patients interviewed experienced more than one diagnosis and in many cases the clinics they attended did not coincide with what the patient considered to be their main health problem. Coordination of care for multi-pathology remained very much with the patient.

5.2.4 The Organisational Whole System

There was evidence in both case study sites of a congruence between the patients' and practitioners' descriptions of the model. In site PCN2 the qualified dispenser at the surgery maintained the disease registries and co-ordinated the review call-up system for all patients with CHD, asthma, stroke, diabetes and COPD. Over the years many patients were now initiating their review before the call-up invitation letter and 'DNAs' had gradually reduced. If DNA patients were known to the dispenser, she would personally telephone them; otherwise they would receive two follow-up letters, the first one to two months after the initial invitation letter.

The nurses at PCN2 agreed that most patients now knew the system and were comfortable with it. Most patients are seen for an annual main review and then six months later for a BP and general check, or more frequently if required (e.g., people with COPD exacerbations, poorly controlled hypertension).

In the PCN1 case study the clinic offers an annual review (20 minutes) with a six-month follow-up (15 minutes) for every patient on the register. Administrative staff use the IT system to generate letters to patients asking them to arrange reviews or follow-ups when these are due. There is a high degree of patient cooperation with the system, with high rates of attendance. The review sessions include routine tests, discussions of symptoms and symptom control, and patient education. Sessions with newly diagnosed diabetics last 30 minutes and are followed up monthly for the first three months. Patients can make additional appointments if required, and there is a weekly slot for telephone consultations. Recently, the clinic has begun to see pre-diabetic patients (those with impaired glucose tolerance and therefore at high risk of developing diabetes).

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> *'Well, [the practice nurse] runs a mainly nurse-led service where she actually does, performs most of the reviews. So when patients are referred to her, she sort of coordinates the annual review and the routine review of patients with diabetes. So she ensures that their bloods are taken and gets everything checked off to make sure that they've been referred to the Retinopathy Screening Service, that they've been seen by the dietician and the podiatrist for their annual assessment and goes through a medication review and a blood test review with the patient. And of course she then refers patients that she has specific concerns with on to either their GP, or her GP and herself will sit down and discuss patients and refer them either then to ourselves, to our service.' PCN1 Local Health Board DSN*

In PCN1 referrals are made as appropriate to podiatry and dietetics services, secondary care, or the diabetics specialist nurse and GP employed by the Local Health Board. Both podiatry and dietetics services provide sessions at the practice, although patients may attend at other sites if they prefer. Retinopathy is provided by local opticians: results are communicated to the practice and entered on patient records, so as to form part of the review system.

> *'I would say that [the service] is very well run, it's very organised and patients have a good access to some very good care and information. So that what you notice when you're dealing with patients of [PCN1] is that they are better informed about their health and their general status… they seem to have a much better understanding of why they've been referred.' PCN1 Local Health Board DSN*

Some patients continue to be treated in secondary care, either because of the complexities of their diabetes or because they prefer to stay with the service with which they are familiar. In PCN1 the administrator who runs the diabetes register does monitor these patients to ensure that routine tests are carried out at the appropriate time.

Housebound patients with diabetes are served by the district nursing service provided by the large combined acute and community health care NHS trust. However, district nurses may find it difficult to prioritise annual reviews, given the other demands on their time.

In PCN2 the nurses spoke of referral pathways, for example the junior practice nurse could directly refer patients to the foot clinic at the local hospital or the local chiropodist, but would ask the GP to refer patients with diabetes to a dietician or vascular surgeon if necessary.

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The nurse run clinics at PCN2 worked particularly closely with the COPD Nurse Specialist and community matron. Previously a hospital based COPD nurse specialist, the former had been in post 1 year and was employed by a PBC cluster of seven surgeries. She focused her role on annual reviews of housebound patients and managing acute exacerbations at home, whilst she described the PCN2 nurse practitioner as managing clinic based annual reviews. PCN2 patients who failed to attend their COPD review are referred to the nurse specialist for follow-up. The community matron is also employed by the PBC cluster plus two other surgeries. Also from a hospital background, the community matron has been in post for 18 months and undertakes "shared care" with the surgeries including PCN2. Although her role is managing those patients (usually older people) with complex co-morbidities with the aim of facilitating self-management, preventing hospital admissions and reducing GP workload, she finds that GPs often find it difficult to let go and continue to visit these patients as frequently as before she was in post. She links well with PCN2 and the nurse run clinics, but there are issues in the relationship between the nurse run clinics and the district nurses. District nurses were no longer based at the surgery which was regarded as a retrograde step by PCN2.

Access to the specialist practice nurse continued to be a problem at PCN1 where the practice nurse works only one day a week at the practice, which she spends entirely in running the diabetes clinic; she works at the local health board at other times. She liaises closely with the GPs at the practice about patients, particularly in relation to prescribing. She is supported not only by the GPs, but also by the DSN and GP with special interest in diabetes. She is regarded as a diabetes expert by colleagues and patients, and because she has run the clinic for nine years, and provides continuity of care.

> '[She] *has become essentially a mini GP in diabetes within the surgery. She's been able to provide the experience, the expertise and the continuity which is what a GP provides in all the other illnesses… I think that anything that provides continuity within primary care is valued by patients.' PCN1 GP*

GPs continue to see diabetic patients with complex medical needs.

Most of the practices in the area provide a nurse run primary-care based diabetes service; the LHB regards the PCN1 service as a particularly well-organised and successful example. Clinicians at the practice and local health board personnel think that the system works very smoothly and that the clinic is very efficiently run, though there are some areas of concern.

- Liaison between the practice and the district nursing service is of limited effectiveness, and information-sharing is not easy. The practice nurse does not have time to do home visits, and GPs do not expect their staff to do this, but the district nursing service is often under-staffed and has to prioritise urgent care over reviews.
- It is sometimes necessary to remind the national retinopathy screening service to screen individuals.

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In both case studies the service contributes to practice income by meeting the requirements of the Quality and Outcomes Framework. In PCN1 an important outcome of the service is that fewer patients are referred to secondary care, which means that expensive secondary care services do not have to expand in line with the increasing prevalence of diabetes.

The data from service providers and co mmissioners of primary care indicate high levels of satisfaction with the organisation of nurse run disease specialist clinics targeted at diseases for which there is high prevalence and a good evidence base for managing these conditions in primary care. Nurse-run clinics appear to be brisdging the gap between generalist patient initiated GP care and specialist disease centred secondary care. Nurse run clinics provide routine service initiated disease specialist care for patients in primary care settings.

5.2.5 The Data System

In both case study sites GP practices retained good patient registers patients were recalled for their annual reviews and six monthly checks and were able to make appointments between these visits if required.

In PCN2 the data system has been of central importance, with the setting up of disease registries and a systematic call-up system. For example, in addition to the nurse run clinics, patients with diabetes are read coded and automatically sent an appointment for retinal screening at a hospital run outreach service. The QOF has also had a significant effect on the model with nurses ensuring that tick boxes are completed during patient reviews. However, as previously discussed there are issues when IT systems differ – illustrated by the district nurses' different system. It was also apparent during data collection that patients are recorded as separate entities on more than one disease register if they have co-morbidities. Hence a patient may be called up for separate annual reviews for CHD and diabetes. In addition, some patients may have to have blood tests repeated that have recently been done in secondary care.

Although there was clear evidence of how the model linked in with other models of nurse coordinated CDM such as condition specific nurse specialists and community matrons, there was little evidence of how the nurse run clinics related to social care systems. This may be more to do with the patient population they dealt with who tended to be mobile and able to self-manage to varying degrees. However, it was also clear that housebound patients were also reviewed by the practice based nurses and the data indicate that any linking of these housebound patients needs to social care was more likely to be undertaken by the GP or other nurse-led models such as the community matron

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In PCN2 the district nursing services were unable to access the GP data systems and found it increasingly difficult to carry out the annual reviews despite regular visits to the patient as they could not register the results back at the GP practice.

> *'…we have got different roles there's no doubt about it. And in fact probably has become more distant over the last couple of years. Because the district nurses were at that time based within the practice and now they've moved to a different location. So it's difficult if we've got a patient who needs to be seen at home and is being seen by the district nurses because they would say "well, we'll do their diabetic check" but we weren't getting the information. So in the end we've had to more or less abandon that and not use them as regards, you know maintaining our patient contact on an annual basis. So now what happens is [practice nurse 2] does go out and do visits at home. So our healthcare assistant, would go out one week and take the blood and then [practice nurse 2] would go and visit the patient at home. Because that way the information was being put on the system in order to meet the QOF requirements and so from that point of view that's how it worked… their paperwork has become just so huge that just to go in and do a diabetic check to justify that, you know they have to do all their assessments and everything as they would for any other patient and they were saying "well, we haven't got time to do it". So in the end if was just easier to take it on board ourselves really.'*
>
> *PCN2 Practice Nurse 3*

The integration of data systems has been identified as a key requirement for chronic disease management (Wagner, 1998). Evidence from this study indicates that data systems are still organised around the prevalence of disease in a given population and not around the patient experience of disease. Hence a patient with more than one chronic disease may be counted on more than one disease register. Data systems cannot therefore be interrogated to identify the impact of service configurations such as nurse run primary care clinics on reducing system costs or improving patient outcomes.

5.2.6 The Whole System

Both services are designed to ensure that regular reviews lead to better management of symptoms, better patient understanding of the condition and its management. The services are also designed to enable longer consultations than are possible with GPs and coordinated appointments with the practice nurse and the podiatrist. Overall, the services ensure better access for patients through a local service with short waiting times, and continuity of care.

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There is no reason to doubt that these outcomes are generally achieved in both case study sites for the specific diseases for which the clinics have been set up. Most of the patients being managed by the primary care clinics demonstrated a good understanding of the service and there was plenty of evidence that the service facilitated self-care management of the specific disease for which the clinic was designed. There were similar findings in both case study sites for most of the patients interviewed who were attending specialist nurse run clinics in secondary care. However, there was evidence that some patients receiving secondary care could have benefited from more input, but these patients tended to be at the more complex unstable end of the trajectory of the condition. There was evidence that patients attending hospital based clinics did not value primary care and assumed it would not be able to offer the same level of clinical expertise found in secondary care. There was evidence that the nurse run clinics in primary care tended to deal with less complex manifestations of the disease. This was particularly the case in diabetes where more complex type 1 diabetic patients tended to be managed either in hospital based clinics where they had access to both diabetic nurse and medical specialists or, in primary care, GP care often supplemented nurse interventions in complex situations.

While the above holds true for the diseases for which specialist clinics were available it is only partially true when considered in the context of the whole patient experience of health and illness. Many of the patients interviewed were experiencing more than one illness with many experiencing up to four different diagnoses. For some patients, diseases, other than those managed by the specialist clinics, were creating more problems and concerns for the patient than the disease for which the clinics were established. There was considerable data in the patient interviews focusing on the other diseases that they were also experiencing and the difficulties of accessing services to meet their needs in relation to these other diagnosis. Some patients in PCN2 had two or more diseases that mapped onto two or more of the specialist clinics provided by the nurses. Again these patients found that each disease was treated separately and the integration of disease management that constituted their everyday experience was something they had to work out for themselves and generally went unrecognised by all the practitioners that they visited. While living everyday with multiple diseases and learning how to balance self-care management of their diseases, patients had to compartmentalise their experience into specific disease categories when visiting a practitioner, whether it was a nurse, GP or medical consultant.

5.2.7 The Causal System

In this context the causal system relates to the factors which perpetuate the continuation of traditional approaches to practice and service delivery even when the evidence and policy drivers indicate the need for change. It also includes those drivers which have been important in introducing and

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sustaining practices which conform to the principles of the CDM model (Lewis & Dixon, 2004).

The data indicate that where patients are receiving nurse run primary care for a specified chronic disease for which specialist primary care nurses and/or clinics are available there is evidence that the care is well managed, informed, pro-active and preventative. Patients value the nursing input and are able to understand and use the services effectively. However, the evidence presented also indicates that the primary care model of CDM presents as a partial rather than holistic model (figure 3). Exceptionally patients can self refer into nurse run clinics, but this depends on the availability of the clinics and on the expectations of the GP practice. It is still the case that patients contacting GP practices outside of their routine clinic appointments are likely to see a GP rather than a nurse, even if the trigger for the contact is the condition being managed via the nurse run clinic. This is because a patient initiated contact indicates an unplanned change in their condition which would normally be seen by a GP. In contrast nurses focus on managing the anticipated trajectory of the disease, referring back to the GP if the patients experience complexities they cannot manage. It is also the case that the organisation of care delivery in the surgery often means that it is easier for patients to access a GP whose day is organised around responding to unplanned appointments and calls including telephone calls, rather than a nurse whose day is organised around planned clinics often booked up well in advance.

The case studies indicate that the relationship between primary and secondary care remains largely intact. Although GP practices are providing far more planned and routine management of chronic disease, they tend to focus on single diseases treated in isolation from each other. Care is geared to meet the needs of the uncomplicated stable patient, emphasising lifestyle management of the disease and routine drug therapy. Anything more complicated tends to be escalated to secondary care where it may remain even after the patient has stabilised again. Patients who have experienced secondary care tend to continue to access it when it is offered as they perceive that secondary care (including nurse coordinated secondary care) is more informed by specialist knowledge from which they feel they benefit.

Patients with multiple diagnoses continue to experience difficulty in accessing services or practice that is designed to provide a coherent response to the differing and often idiosyncratic range of diseases with which they present. This is as true for secondary care as for primary care. Therefore the medically dominated disease centred model of service provision continues unabated for patients with multiple diagnoses despite all the policy changes.

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The data system has been critical to the implementation of the nurse run primary care model and provides the infrastructure through which the model operates. Included in this is the QOF system of contract monitoring and the patient registers and recall systems necessary for effective QOF management. However, while this has clearly been instrumental in developing and sustaining a primary care nursing model of CDM, it has also limited the scope of the model to single diseases recordable on a disease register, rather than building and sustaining a primary care nursing model designed from first principles to focus on patient needs.

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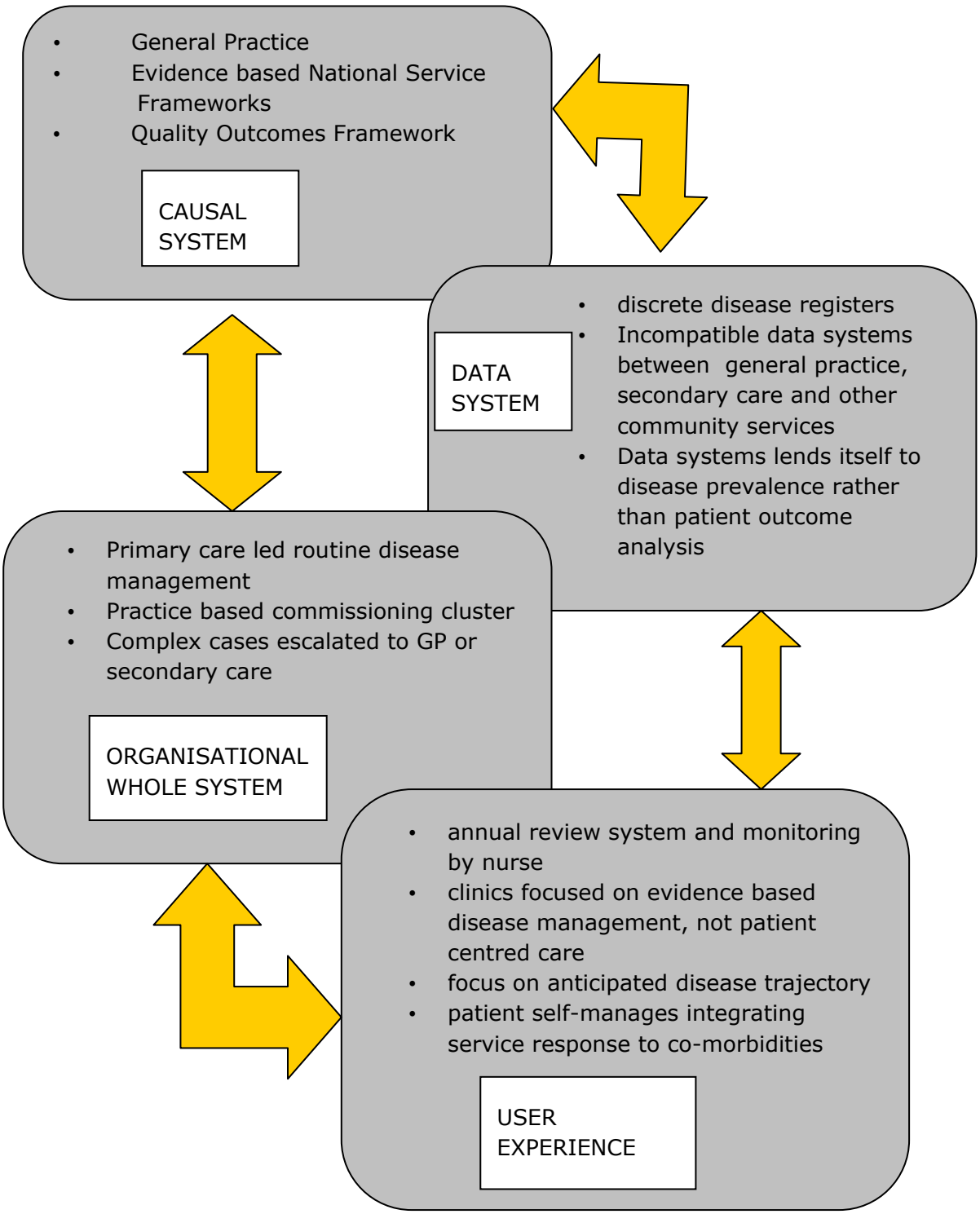
Figure 3. The primary care nurse model and whole systems framework



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5.3 Nurse specialist model

Two case study sites provided the data for this model. Both were based within secondary care but as described in 2.5.3, the NS1 model was a single nurse specialist, who while working with other colleagues within her department, provided a service for people with epilepsy virtually single-handedly. NS2 was made up of a team of nurse specialists and other practitioners who provided a comprehensive service for people with diabetes, particularly those with type 1 diabetes.

5.3.1 Epilepsy Nurse Specialists

It is estimated that about 440,000 people in the UK are affected by epilepsy (Joint Epilepsy Council, 2008) and there is general agreement that people with stable epilepsy are best treated within primary care. However, while GPs can expect about 15 patients on their caseload to be diagnosed with epilepsy, a number of audits in the 1990's indicated sub-optimal care (MacDonald *et al,* 2000). With role expansion for nurses (Department of Health, 2000a) there was a move towards the development of ESN roles with some studies suggesting that this role had a significant impact on patient psychological status (Ridsdale *et al,* 1999), patient satisfaction and adherence to medication (Mills *et al,* 1999a; Mills *et al,* 1999b). A report from the Clinical Standards Advisory Group on services for people with epilepsy (1999) described the role of the ESN as acting as a contact point for GPs seeking advice and holding outreach clinics, facilitating fast-track referrals, acting as a resource for information about the strengths and weaknesses of the range of services in the local community (medical, statutory, voluntary) for GPs and hospital clinicians, and training practice nurses and volunteers.

However, in many cases the role has significantly expanded further and may incorporate all three core nursing functions: diagnosis and treatment at first contact care, continuing care and CDM, and public health and health protection (Department of Health, 2002). Regardless of NICE guidelines (2004) stating that ESNs should be an integral part of the network of care, and the NSF for Long Term Neurological Conditions (Department of Health, 2005b) also emphasising that prompt access and availability of an ESN is a good practice marker, a report by the All Party Parliamentary Group on Epilepsy (2007) described persisting failures in the health system. Despite ESNs being 'a crucial source of support and advice to patients with epilepsy' and enabling 'many patients to manage their epilepsy effectively and to remain independent in the community', the report argues that there are insufficient numbers of ESNs. There are approximately 152 ESNs in England but epilepsy groups have been

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lobbying to increase this to 920 (All Party Parliamentary Group on Epilepsy, 2007). Furthermore, a significant number of ESNs in post feel threatened by redundancy (All Party Parliamentary Group on Epilepsy,2007), a scenario familiar to many nurse specialists as a result of workforce planning post Agenda for Change (Department of Health, 2006b).

5.3.2 Diabetes Nurse Specialists

Three million people in the UK have diabetes (Diabetes UK, 2010), and of these people 5 to 10 % will be affected by type 1 diabetes, but the vast majority will be living with type 2 diabetes (BMJ Group, 2009). By 2010 it is estimated that 3 million people will be affected by diabetes. Although diabetes is increasingly being viewed as an endemic problem linked to lifestyle, it is also a long term condition in which specialist nursing intervention has been common. The role of the DSN was first introduced over 60 years ago to educate and support people living with diabetes and their families at all stages of their lives. The role became more common in the 1980s with the introduction of self-monitoring of blood glucose and changes in insulin medications, however there continues to be much variation in job descriptions and function (Humphris *et al,* 1999). The NSF for Diabetes clearly articulates the enablement of self-management as a central facet to the role (Department of Health, 2001a) and exemplified the role in secondary care provision. However, at the same time there was an increasing move of diabetes management to primary care resulting in a significant expansion of community based diabetes nurse specialists. Their role includes insulin adjustment, and cardiovascular disease risk reduction (Nursing Times Net, 2006). The DSN is seen as part of a broader team approach to diabetes management which needs to span primary and secondary care and includes the development of several new roles (NHS Modernisation Agency, 2002). In 2007 there were 1,278 DSNs working in the UK (Diabetes UK, 2009a).

5.3.3 NS1 case study site

The NS1 case study site is close to the centre of a large town in the East Midlands. The model is a hospital based, condition-specific (epilepsy) nurse specialist, the first ESN to be NHS funded. The ESN provides support for a team of more recent nurse specialists within the department; a headache nurse specialist, two MS (multiple sclerosis) nurse specialists and a Parkinson' Disease nurse specialist who is mainly based within the community. The ESN is line-managed by the head nurse of the directorate. There is a total catchment of 350,000 patients served by the neurology department, of which people with epilepsy are the most common. The ESN on average sees about 25 patients per week comprising new patients (5), follow-up patients (16) and others, patients are mainly

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referred within the county although others from outside of the county may be referred to the service.

The county has a population of 669,100 (mid year 2006) with a significant anticipated growth in the population by 2016 of 14.6 percent to 766,600 compared with a rise of 7.8 percent for England.

Table 10 shows the proportion of ethnic minorities to be much lower than in England, however there are two local authorities within the county that have an ethnic minority population of 8 percent to 9 percent, higher than the county average. The county is essentially rural but with several large towns. (East Midlands Public Health Observatory, 2007). There is a mixed picture for relative deprivation across the county with some hotspots, one LA is in the bottom quintile of LAs nationally for relative deprivation.

Table 10. Demographics of county

County		England
% ethnic minorities in population	4.9 %	9.1%
Population density (people per hectare)	2.7 3.8	
% people of working age in employment	80% 75%	

Office for National Statistics, 2004a; Office for National Statistics, 2008)

The epilepsy prevalence rate for the PCT is 5.5 cases in every 1000 which is slightly lower than the England rate of 6 cases for every 1000 population. Ninety-five percent of epilepsy patients had had a review and were on drug treatment for epilepsy and approximately 73 percent of patients on drug treatment had been convulsive free for the last 12 months (recorded in the previous 15 months), similar to the national figures (National Centre for Health Outcomes Development, 2008). Ninety-five percent of patients in the PCT and England recorded at least one seizure in the previous 15 months (National Centre for Health Outcomes Development, 2008).

5.3.4 NS2 case study site

The NS2 case study site is in the East Midlands.

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The model is a hospital based, condition-specific (diabetes) comprehensive clinical and patient education model aimed at behavioural and lifestyle change. It has developed over a prolonged period of time, its origins going back three generations of practitioners to the 1940s and 1950s. The emphasis since the foundation of the model has been on patient education including expert patient programmes (Department of Health, 2001b), DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) and DAFNE (Dose Adjustment for Normal Eating) Programmes and on promoting patient independence and reducing dependence on hospital care.

The county has a population of 934,000 (2007), however almost one third of these people live within the city. Based on 2006 populations the number of people aged 75 and over is expected to increase in the next 10 years by nearly a third outside the city but by only 8% within the city. Table 11 highlights that more than a third of the population in the city are from black and minority ethnic groups, compared with the national average of 9.1 percent. However there is a range outside the city from around one to 16%. The city is very densely populated, with 10 times the number of persons per hectare than nationally (Office of National Statistics, 2004).

Table 11. Demographics of county

Ci	ty	Outside city	England
% ethnic minorities	36.1	5.3	9.1
Average population density (persons per hectare)	38.2	2.9	3.8
% people of working age in employment	66	76	75

(Office of National Statistics, 2004a; Office of National Statistics, 2004b; Office for National Statistics, 2008)

There is a mixed picture for relative deprivation across the county with the city being in the highest relative deprivation levels and areas outside experiencing relative affluence. This is also highlighted in that people in the city area have poor health status with lower life expectancies and premature death rates from all causes, circulatory disease, and cancers compared to the rest of the county. (Association of Public Health Authorities, 2008; National Centre for Health Outcomes Development, 2008; East Midlands Public Health Observatory, 2007).

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It is estimated that one in three adults smoke, one in four are obese and one in four eat healthily. The average number of smokers is higher in the city than the East Midlands and England average (Association of Public Health Authorities, 2008).

The estimated diabetes prevalence rate is between 4.5 percent and almost 6 percent with the highest rates being in the city compared with an average of 4.8 percent for East Midlands and 3.7 for England. (Association of Public Health Authorities, 2008).

5.3.5 The service user experience

In NS1, seventeen patients and four family carers were interviewed. In NS2, eleven patients and three family carers were interviewed.
Both people living with epilepsy and those with diabetes reported common experiences of their condition. Fear of seizures and hypoglycaemic attacks were frequently described by service users and their carers. Also commonly reported was the perception of stigma of having the condition. Whilst this is well documented in the case of epilepsy, the increasing focus on lifestyle as culprit, particularly in type 2 diabetes, contributed to a sense of shame and stigma in service users with this condition. Therefore, a particularly important outcome of this model was the ability of the nurse specialist to reduce the stigma at a personal and organisational level. For the former, communication with the nurse specialist was described by many patients as being reassuring, providing explanation, caring and accessible:

> *'The second time I saw [Epilepsy Nurse], I felt so at ease with her, I felt like I could ring her rather than bothering the GP. I felt I would get a quicker response from [Epilepsy Nurse] anyway than the GP.' NS1 Patient 5F*

For all service users, the immediate days after diagnosis were particularly difficult and it was important to them that the nurse specialist provided traditional notions of 'comfort':

> *'…they were lovely... I mean, she was very sympathetic and very conscious of the fact I was quite young to get it and it was quite a big shock for me. She gave me her home phone number as well which I know now was a real extra thing, you know, because I was so worried about it. She said if ever I needed anything to give her a ring.' NS2 Patient 2F*

Once respondents had come to terms with their diagnosis, the nurse specialist was seen as an invaluable source of practical tips and as having more specialist knowledge than the doctors.

> *'I've always, like I say, felt very comfortable with talking to the nurses. I do think they are very knowledgeable. I mean, like I say, they offer solutions to me. When I have problems in terms of*

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tweaking my insulin or anything ar ound that, they offer a solution to me.' NS2 Patient 1F

However, in NS2, despite an acknowledgement by most respondents that services were increasingly nurse run, there was a persistent belief that the nurse's role was just to monitor the condition rather than to have any role in diagnosis or treatment. When asked whether they would be happy to be totally managed by a suitably qualified nurse rather than a doctor, the vast majority of respondents wanted to continue with overall management by a doctor. However, when probed further this was not due to any concerns about the nurse specialists' skills or competencies, rather it was a response reflecting the familiar and expected division of labour:

'It would be quite strange not to have a doctor, but I don't think it would be… mainly it's just from conditioning really, it would feel odd. I don't think it would be anything.' NS2 Patient 4F

This was in contrast to NS1 where the nurse specialist was clearly recognised as a medical expert:

'…you know you look at her for more the expert…she's more in tune with it really. I mean all my doctor's going to do is send me to her. So you're just cutting out the middle man really.' NS1 Patient 4M

This confidence in the nurse specialist's competencies and expertise resulted in the majority of patients using her for first contact if any problems arose with the condition. Service users would also use the nurse specialist as the first point of contact because of the accessibility of the model. In NS2 this resulted in a 'trade off' for many respondents in accepting nurse-led rather than doctor-led management because it resulted in patient issues being dealt with more rapidly.

Service user contact with the service delivered within the model was similar in both sites. Patients whose condition was poorly controlled would be reviewed every six months or more frequently. Those with better control had an annual review and service users with good control were increasingly likely to be discharged to primary care led management. Both sites were open to patient contact via a helpline in between appointments. While the availability of ad hoc contact with the nurse specialist when needed was highly valued by service users, there were some reservations about delays in response to enquiries, and in the case of NS2 having to deal with different staff that were unfamiliar. Respondents in both sites identified the lack of support available outside of 9 to 5 weekdays and in NS1 service users reported there was no cover when the nurse specialist was away. Nevertheless, some patients with epilepsy reported that their treatment was totally managed via telephone contact with the nurse specialist.

The experience of the review in each site was very different. In NS2 it entailed seeing a number of professionals in turn:

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> *'You sit outside on a little chair, go into one room and then move down and go into another. .. normally a lady checks my blood, checks my weight, takes my urine and then I go and have my bloods done and I get taken into an other little room and I have my BP checked, my feet checked, all my sites of where I inject myself checked… then I go and see my specialist nurse. Usually there is a dietician there as well…' NS2 Patient 1F*

It was also likely that service users within the NS2 site would need to access clinics in different locations for the various aspects of diabetes management; for example eye care, renal care and so on. For the majority of respondents this did not appear to be problematic, but this may reflect that patients needing more services were likely to have lived with the condition for a number of years and grown familiar with the routine:

> How do you feel about going from here to there?
>
> *'Alright, because I know what I'm doing. It's like in business, I know in effect, like I can do a job there and I can do a job there and a job there, it's a job as far as I'm concerned, keeping me going.' NS2 Patient 6M*

In contrast patients in NS1 would only see the nurse specialist, with the clinical encounter following the traditional consultation model, and if needed patients would be referred for investigations or prescribed changes in treatment.

The management of diabetes is significantly focused on physiological measures and service users were fully informed of test results:

> *'I get a letter very, very promptly, usually within the space of a couple of weeks. From my review I get all my results. A copy also goes to my GP and I actually get the same copy as my GP gets. Every single time that I have an appointment, whether it's with a nurse or whether it's the dietician or at my review, I do get information. It's just literally like a review and recap of what was discussed anyway but, yes, I always get something in writing from them.' NS2 Patient 1F*

However, the relaying of results appeared inconsistent, with some respondents relying on the GP to forward their results:

> *'I think the hospital sort of send a copy to the GP and then the GP sort of has a look and then forwards it, a copy onto me.' NS2 Patient 4M*

In NS1, patients were copied into letters sent from the nurse specialist to their GP.

Service users' experience of self-management facilitation varied between the sites. Within NS2 there was a strong emphasis on structured self-management education interventions, and many respondents had completed the DAFNE course. Most were positive about the experience,

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describing how it had enabled them to take a more flexible approach to their diet and lifestyle, and had increased their understanding of diabetes. They particularly valued meeting up with others in a 'non-hospital' environment. Although epilepsy also requires effective self-management there was no structured educational intervention available. The majority of respondents had been provided with some information by the nurse specialist but many had found out about the condition themselves:

> *'…obviously at the beginning I looked it all up on the internet, found out all about my particular type of epilepsy and the medication and I don't really feel as though there's anything else I need to know about it now you know. At the time it was useful but I don't feel as though I need it now.' NS1 Patient 8F*

5.3.6 The organisational whole system

The model in both sites was largely dependent on interactions within a complex whole system. However, the nurse specialists' accessibility for service users was in NS1 a discrete action by the individual nurse specialist's helpline, and in NS2 the giving of nurse's home telephone numbers to newly diagnosed patients with type 1 diabetes. This latter activity was described by several respondents (all young and female) and although greatly appreciated by the service users, any impact on the nurse themselves is not clear. The helpline in NS1 was perceived as problematic by service users during out of hours or when the nurse specialist was away.

All other activities of the nurses within the model were entwined with other professionals and services. The NS2 based large diabetes multi-disciplinary team is split across the two hospital sites which work together and link professionally dietetic colleagues on a regular basis. There are regular clinical governance team meetings and general clubs which are multidisciplinary where people come together to discuss cases or problems or for education or tutorials. Nurses on the diabetes team work on the hospital wards but also circulate to outpatients and primary care clinics. This enables them to keep their skills up to date and to see patients in different settings and so get the hospital admission into perspective in respect to the patient's life and self care management. The NS1 team is much smaller but the nurse specialist also works within a larger multi-disciplinary team. There are regular monthly neurology meetings within the hospital, and in addition the nurse specialist has regular contact with the maternity and paediatric teams within the hospital.

Despite barriers to a whole system caused by separate budgets and the commissioning process, the model continues to span the secondary and primary care interface. Within NS1 the nurse specialist links with the

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learning disabilities team, practice nurses and GPs, school nurses and the community nursing service:

> *'…she does go around the health centres as well and see the treatment room staff just to give them information and support them as well. Because people just sort of appear, don't they, in front of them, the treatment room sisters. So she's got a good link with them as well.' NS1 Community learning disabilities nurse*

Active promotion of the whole system approach is enabled by the NS1 nurse specialist's 'countywide' – an event run by her which brings together key stakeholders in epilepsy management:

> *'When she does the countywide, we get involved with the district nurses and the school nurses because they get invited and we also get involved when the hospital nurses come along to her countywide.' NS1 Community learning disabilities nurse*

The much larger team in NS2 resulted in many of the nurses within the team promoting a whole systems approach. The nurse consultant is leading on a new project with nurses setting up intermediate care clinics in primary care involving multi-disciplinary teams including health care assistants, dieticians and podiatrists. Many of the nurse specialists divided their time between secondary care and supporting GP practices, and it was hoped that this model of working would be increasingly commissioned. In addition, the team at NS2 were involved in the delivery of the DAFNE and DESMOND structured self-management programmes for people with diabetes types 1 and 2. These are mainly delivered in the community, and although dependent on commissioning, is another example of whole system working. Commissioning has bought with it the challenge of trying to identify the characteristics of patients who can be managed exclusively in primary care and those who would need referral to secondary care because of additional complications. Currently the diabetes team are working on a commissioning model based on patient characteristics indicating the type of care required which does not specify provider but instead specifies the level of skill or competency required to manage the patient effectively. The main problem envisaged for commissioners with the proposed care model is how to replicate education, training, supervision, mentorship, visiting practices, providing training for other GPs, surgeries and so on that is currently found in hospital team.

Research activity in NS2 also enables whole systems working and is host to a wide range of research studies in diabetes. For instance it hosts the local research network for diabetes as part of the UK Clinical Research Network as well as being engaged in a wide range of clinical trials and evaluations of patient education programmes. The research is led by a medical consultant who is also a Professor in Diabetes Medicine who manages a large research team. Much of the work undertaken is around applied research designed to address everyday problems of diabetic management. More recently a primary care research interest group has been established who meet with the hospital team regularly both for

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educational development but also to identify opportunities for involvement in research projects, to promote recruitment of patients directly from primary care and to run research from GP practices. As a result research, service development and practice have evolved together and are strongly interlinked. Many of the nursing and allied health practitioners we interviewed who provide care for diabetic patients entered the diabetic service initially via involvement in clinical or evaluation research and most maintain an active interest in research and in service evaluation supporting patients to participate in these activities.

The nurses in both sites exemplified whole system working. They saw liaison as a key part of their role, building bridges and developing new ways of working with other sectors and services. This role was enhanced when their expertise was recognised and acknowledged by other disciplines and sectors. This was strongly apparent in NS1 where the nurse specialist was recognised across the county, and indeed nationally and internationally as having significant expertise in epilepsy management:

> *'I think she takes on enormous responsibility which is… I mean she is very experienced and she is actually extremely able and I think if she weren't there I think we would miss her terribly… I mean she's the Consultant for Epilepsy in this area really.' NS1 GP*

At the heart of all the nurse specialists' work was the desire to improve care for the service user:

> *'…it's a different way of working, and it's a new model of care, but its just going to be a project that we're going to be involved in for the next two years, and if it works very well, we hope that it does work very well, that they will commission our services, that we nurses can go out there and provide the diabetes care, for people with diabetes on their doorstep really…It has to be patient orientated, it isn't for us. Its 24/7 they live with the disease, I feel that we've got to motivate them, we've got to empower them, we've got to make sure that they know how to manage their diabetes, and we just facilitate it. And I think by facilitating it is once or twice they see us, or three times, I don't know, we just facilitate it and make sure that they're on the right track. They do fall off every now and then, we pick them up and put them back again.' NS2 Diabetes matron*

However, ways of helping the service user navigate the whole system appeared less well-established. As discussed in the next section, service users particularly appreciated access to the clinical monitoring data system, but often found it difficult to easily contact the range of clinicians involved in their care. Within NS2 some patients had started to use email communication:

> *'there's certainly on our headed paper we have, the secretaries all have our e-mail addresses and if they, I mean I've had patients e-mailing and eye photographs they've had done at the optician, blood results, different things, queries to direct onto the Consultant*

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really because obviously now technology is advancing and that's fine, if it's as easy to communicate via e-mail then that's fine with us.' NS2 Administrator

This was likely to be an evolving communication system that would help many patients.

5.3.7 The data system

The data systems in each site were very different. In NS2 a clinical monitoring system had been established in 1997 and was managed by a full-time administrator. This recorded all diabetes data including blood sugar, BP, height and weight. Data were entered during the consultation and the service user was provided a letter with all the results and suggestions for ways of improving control at the end of the appointment; however data from service users (5.3.5) suggest this was inconsistent. The GP was also sent a copy of this read-out. The system was also available for use via a modem at satellite clinics and recorded co-morbidities. Data could be translated into graphs which were often used as a patient teaching aid. The system also incorporated an email facility which was used by the various clinicians (doctors, nurses, dieticians and so on) to communicate, and a journal where any hospital admissions and progress was recorded. The system was overseen by the Consultant Head of Service and any issues were addressed at the bi-monthly clinical governance meetings. Data produced by the system were also drawn upon for research purposes. However, the system used at one of the main hospitals was different to the one used at the other hospital and it was impossible to link the systems over the entire diabetes service. If a service user received care at both sites then they would be entered on both separate systems.

Service users within NS2 with diabetes and renal disease identified password protected access to the renal database as particularly helpful:

'One thing they do which I think is absolutely brilliant is the renal clinic belong to a United Kingdom group which has a renal website, it's called renalpatientsview and I can pick up my results from my last appointment generally within a couple of days… this is how I know what's happening precisely to my kidney function.' NS2 Patient 1M

Although service users with diabetes did receive their blood results on a read-out at the end of the consultation, the ability to enter the website and track renal function appeared to give service users an enhanced sense of control.

Data in NS1 were not routinely collected. Patient records were written by hand during the consultation but there was not routine recording of BP or other clinical data. Although the nurse specialist was provided with a

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computer, her clinics were held in other department's consulting rooms where there was no access to a computer:

> *'IT is very good, we've all got our own PC's, desk PC application. But in clinic it's more difficult because you don't have the, you don't necessarily have access to even a telephone or a PC in the actual clinic situation. I mean in hospitals they tend not to use the PC's quite so much but I suppose if you wanted to look at results it's just not available.' NS1 Nurse Specialist*

During the data collection 104 patient records in NS1 were trawled for clinical data. Just less than one third of records contained information about seizure rate but this was not recorded in a systematic way. Co-morbidities were recorded for two thirds of the patients. However, there is less reliance on physiological outcomes within the management of epilepsy and access to clinical data was less of an imperative for service providers and users in NS1 in comparison to NS2. Overall, service users in NS1 did not appear to want more access to data and they were routinely copied into letters to their GP.

5.3.8 The causal system

In both sites the origin of the nurse specialist model was triggered through a medically defined need. Equally they emerged within a context that saw increasingly active and informed service users, a health service that not only was resource constrained but also challenged by rapidly expanding technology, and increasing needs and barriers to interact across health and social care sectors. The model has also evolved within a health care delivery system constantly driven by a disease focus.

As described in 5.3.4 the NS2 model emerged in a specific and gendered historical context, however the trigger operating in this model appears to be one of growing critical awareness by senior hospital clinicians of the limitations of hospital based medicine and indeed an intellectual and clinical understanding of the need to link health care practice to lifestyle considerations for patients with diabetes (figure 4).

Over several decades the hospital based diabetes team seem to have operated within a virtuous cycle which repeatedly provided confirmatory evidence for developing innovative primary and intermediate care services for patients with diabetes based on patient centred principles promoting patient education. By chance the model is located in an area of the country with an increasingly high prevalence of diabetes partly as a result of the changing ethnic mix of the local population over the last few decades. This creates new challenges for the team in developing programmes to meet the specific cultural needs of different population groups which again reinforce patient centred approaches to care provision. The NS1 model was initiated 13 years ago by the appointment of a neurologist with a special interest in epilepsy, resulting in an increasing amount of referrals and workload. The appointment of a dynamic and

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enthusiastic nurse to the role of nurse specialist had a profound ripple effect. The consequence is a cycle of ever increasing skills, respect and reputation with resulting expansion of referrals and advisory role. The data suggest that this was enabled in a particular context. First, the nurse specialist has shared a close working relationship with the neurologist within a small team. There was an initial freedom to carve out the role and the team has developed further under the auspices of the neurologist and nurse specialist. Many of the respondents suggested that the nurse specialist's personal attributes played a major part in the success of this model; she is highly motivated, evangelical about the role and inspires the confidence of other clinicians, including doctors, of her skills. It is unclear whether the success of the model would be sustained if she was replaced by another nurse; however it was felt that her way of working could be replicated by another because the framework of communication was so firmly rooted:

> *'If somebody new came in, I think she's already made the routes in. So if somebody did, if she le ft tomorrow, and a new lady or a new gentleman came in, we would be after them.*
>
> Yes. Yes, she's kind of created that…
>
> *Yeah. And although it wouldn't be the same for a while, I think we would be able to help the person settle in and get some grounding.'*
> NS1 *Community learning disabilities nurse*

In both sites the model's causal system shared similar characteristics. First, the model works under a disease focused system underpinned by evidence based medicine exemplified by NICE guidelines and NSF's. The model follows a template drawn from medicine and sustainability is significantly dependent on the championship and protectionism offered by senior medical clinicians. The model is further sustained by epidemiological imperatives such as the rise in diabetes prevalence. Department of Health policy drivers also play an important part within the causal system. A focus on self-management in LTCs gives particular impetus to nurse run enablement of self-management within the NS2 site. Nevertheless, the shift of LTC services from secondary care to primary care has often not been accompanied by a shift in expertise. The data suggest that secondary care based nurse specialists have the depth of expertise to provide a cost effective outreach service.

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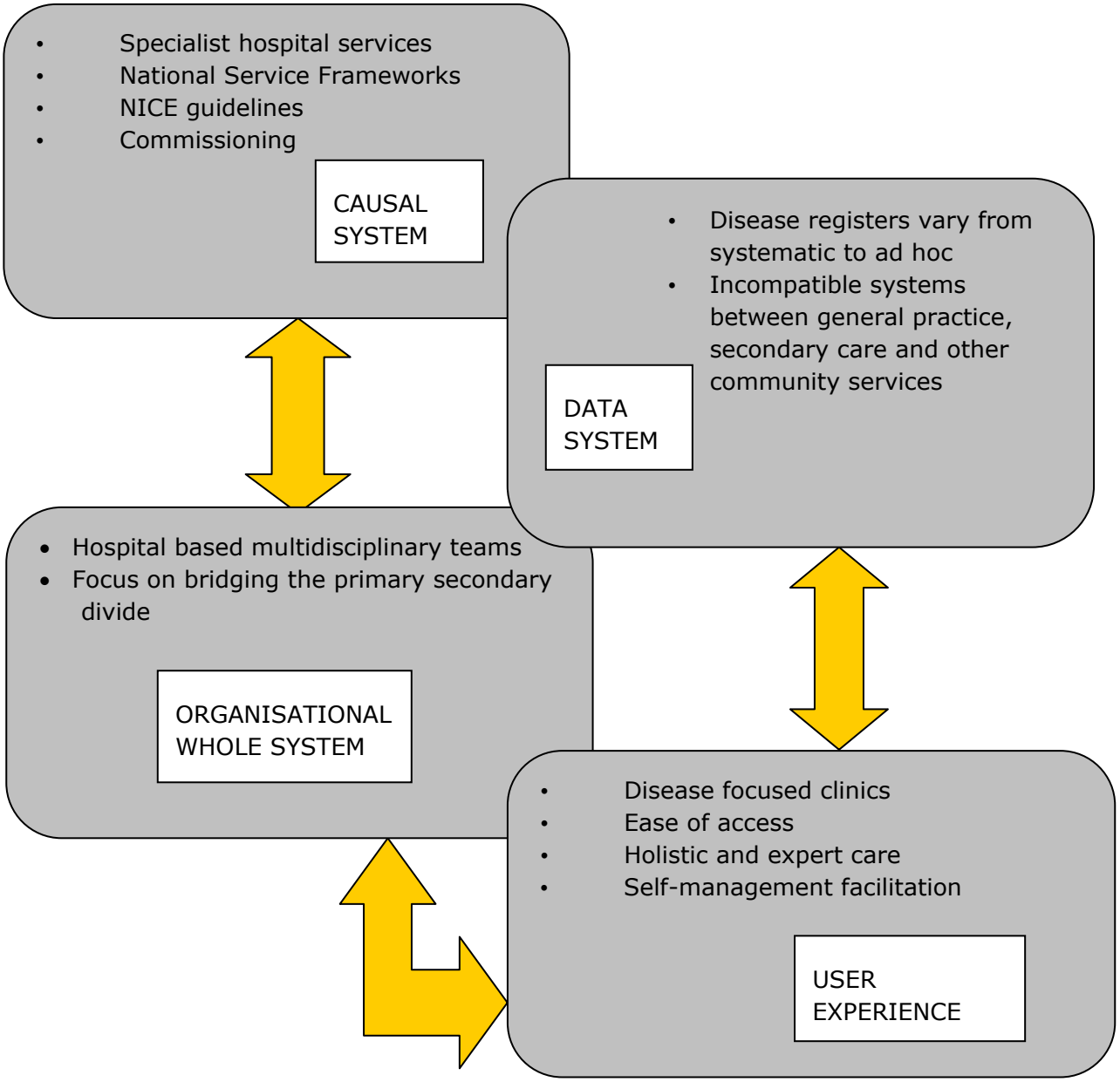
Figure 4. The nurse specialist model and whole systems framework



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5.4 Community Matron Model

The model in two case study sites (CM1 & CM2) is nurse coordinated case management. In CM2 this is delivered via PCT employed community matrons who work alongside PCT employed case managers with a social care background. The PCT in CM2 had been formed in 2001, the model had developed from a pilot started in 2007 which was a response to the Department of Health policy drive. At the time of data collection, four community matrons were in post and each had a caseload of approximately 50 patients and had developed the skills and competencies described in the education framework (Department of Health, 2006a). In addition, district nurse team leaders had undergone further training such as independent prescribing and their role was also described as including case management, and therefore they were included as respondents in the case study.

In contrast the PCT responsible for the CM1 case study was an amalgamation of three PCTs that had occurred in 2006 after the original case study selection process. This impacted significantly to the problems in research site viability described in 2.5.3, not least because the previous PCTs had three different models of case management; an interventionist approach with community matrons having a caseload of 10 to12 very high intensive health services users, a more conventional case management model with each community matron having about 20 to 50 patients on their caseload, and a hybrid model where a crisis intervention nurse worked with two proactive case managers.

In each site community matrons had a designated senior practitioner to provide clinical support and were managed within adult community nursing services alongside district nurses.

As described in 2.5.3, we had considerable difficulty in recruiting respondents from this model, therefore our analyses of this model is based on limited data. We were able to interview six patients and two family carers in CM1 but no health professionals. In CM2 we interviewed four community matrons, one district nursing team leader, one community matron manager and one nurse practitioner who was acting as the community matron facilitator. However, we were unable to recruit any patients or informal carers from this site (see 2.8).

5.4.1 Community Matrons

The increasing demands placed on health services as a result of endemic chronic disease led the Department of Health to explore models of effective working within CDM. In particular there was a need to find ways of reducing spiralling health care costs, for example by reducing unplanned hospital admissions. Despite the fact that the UK achieves better value for money in health care than the US (Ham, 2005), there has been great interest in specific US health systems such as Kaiser Permanente and Evercare. Ham *et al* (2003) study uncovered a number of factors linked to increased efficiency when compared to the NHS.

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Integration, particularly of primary, secondary and tertiary care was found important. There was also greater emphasis on prevention of illness, self-care, and active management of patients either to prevent admission or to facilitate hospital discharge to specialist intermediate care. The case management model was identified as a key approach in reducing unplanned admissions and in 2003 United Health Europe piloted the Evercare case management model in nine English PCTs. In 2004, case management was rolled out nationally as part of the Department of Health's strategy of community matrons (Department of Health, 2004b; Department of Health, 2005d) and a target was set of 3000 matrons to be in post by 2007. However, a RCT and economic evaluation of the nine pilot sites indicated no significant reduction in unplanned admissions (Boaden *et al,* 2006), and in 2006 the national target for community matrons was removed. In the same year an education framework for community matrons and case managers was produced (Department of Health, 2006a) and by 2007 nearly two thousand community matrons were in post nationally.

5.4.2 CM1 case study site

The PCT responsible for the CM1 case study is in the West Midlands. It has a population of 220,000 (mid year 2007) with a projected increase of only 3 percent by 2016, compared with 7.8 percent for England. The proportion of those aged 75 and over is slightly higher than in England and is expected to increase by almost one fifth by 2016, compared to the 16 percent increase for England (Office for National Statistics, 2008).

Table 12 shows there is a very low percentage of ethnic minorities; 2 percent compared with 9.1 percent in England (Office for National Statistics, 2004). Large parts of the PCT are rural but there are highly urbanised areas with much higher population density.

Within the PCT there are pockets that fall into the most deprived 10 percent and 20 percent most deprived Super Output Areas (a UK geographical unit used for statistical analysis) nationally (2008[7]).

[7] The full reference has not been given as this would identify the case study site location.

Table 12. Demographics of PCT

PCT		England
% ethnic minorities	2.0	9.1
Average population density (persons per hectare)	Not calculated by ONS	3.8
% people of working age in employment	80	75

(Office for National Statistics, 2004a; Office for National Statistics, 2004b; Office for National Statistics, 2008)

Looking at LTCs, some conditions such as hypertension, asthma and CHD have a higher prevalence compared to the national rate. However there are wide variations within GP Practices (The Health and Social Care Information Centre, 2008). The estimated percentage of smokers (2000 to 2002) is not significantly different from the national average (Association of Public Health Authorities, 2008) but the estimated prevalence of obesity is 25 percent, statistically higher than the England average of almost 22 percent (The Health and Social Care Information Centre, 2008).

5.4.3 CM2 case study site

The CM2 case study site is in a PCT in an inner city in the south east of England. The PCT has a population of 215,000 (mid year 2007) with an increase of 15 percent by 2016, twice that for England. The proportion of people aged 65 or more living in the PCT is predicted to fall by around 13 percent (Office for National Statistics, 2008).

Table 13 shows a very densely populated PCT with a much higher proportion of ethnic minority groups and a lower proportion of people in employment than in England. The PCT is in the third most deprived LA in the England (Office for National Statistics, 2007c).

Table 13. Demographics of PCT

PCT		England
% ethnic minorities	50	9.1
Average population density (persons per hectare)	100	3.8
% people of working age in employment	61	75

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(Office for National Statistics, 2004a; Office for National Statistics, 2004b; Office for National Statistics, 2008)

Life expectancies at birth are lower and all age all cause standardised mortality rates are higher than for England (Office for National Statistics, 2007a; Office for National Statistics, 2007b; Office for National Statistics, 2008). The actual prevalence of diabetes in the PCT was 4.2 in 2007 which is significantly higher than the prevalence of 3.7 in England. (Diabetes UK 2009b).

5.4.4 The service user experience

Service users receiving community matron input were characteristically likely to be frail and be living with a number of LTCs. For example, one service user respondent in CM1 had a history of osteoporosis (with fractured vertebrae), Menders Disease, breast cancer, stroke, thyroid problems, asthma, venous ulceration, glaucoma, cataracts and depression. The community matrons had strict criteria for which patients would be suitable for their caseload including; the patient having two or more LTCs, a complex drug regimen (polypharmacy), had visited the emergency department twice or more or had had two or more unplanned hospital admissions in the past twelve months, made frequent visits or call outs of the GP, and were not already under the care of a condition specific nurse specialist. While some respondents were vague about the community matron's input, most could clearly identify the nature of the role. Input was described as varying between intensive during acute exacerbations and less frequent visits at other times for maintenance. During the acute phase respondents were very aware and appreciative of the aim of preventing hospital admissions:

> *'…when I was bad this last time, she said "we'll try this so you don't have to go into hospital" didn't she? She decided on the nebuliser and the oxygen.' CM1 Patient 1F*

Community matron's clearly articulated this as an aim of their role:

> *'I've learned roughly when they'll call the ambulance so I'll see them before then!' CM2 Community matron 2*

> *'But definitely from the phone calls that the Community Matrons receive, you know people, clients are starting to phone them rather than you know, a hospital or the ambulance.' CM2 Adult community nursing manager*

The community matron was also seen as removing the need to access other resources such as routine visits to the GP.

A major component of the role as described by service users was physical assessment:

> *'Well today she's done the obs they call it, where she puts a thing on my finger and it does your oxygen and everything, and she said that was good…She's listened to my lungs and my heart, and she's*

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taken my temperature. She has a look at my feet, because I get them very swollen from time to time, but at the moment they're behaving.' CM1 Patient 2F

Following on from a thorough physical assessment most respondents described being regularly prescribed medications by the community matron. The data also suggested that another key attribute of the community matron was the action of appropriate referrals to other agencies and 'organising' care for the service user:

'I've started having trouble standing up in my back and legs and I just happened to mention to her that I was looking for a stool so I could sit on that in the kitchen while I prepare me meals and she said "oh don't buy one, I'll get you one", the next day, at least that week they got me a stool…because I've been buying everything, like I bought a walking frame and they said "why did you buy that", because I said "I didn't know where to get one from'.

… you haven't been made aware at all of the things which might be available to you?

'Since (CM) and like them other nurses been coming, I hadn't before that, no.' CM1 Patient 4M

The majority of respondents clearly identified the community matron as being the enabler of the chronic care approach, whereas the GP was perceived as providing acute care. Therefore, the majority of service users stated that they were unlikely to contact a GP about any problems associated with their LTCs, rather they would use the community matron as first contact:

…would you call your GP instead of the Community Matron or vice versa?

'We don't call him do we now… we don't go up there very often other than if she's due for a blood test or something like that or if she's really ill or if she's fixed something up. I mean this illness she's just had is sort of ongoing, it's if she gets an infection in her chest or whatever then the sputum starts, her chest gets tight so then she goes on these, we've got to the stage where we can start her off on these antibiotics, then I ring (CM) and she'll come in and then if she thinks it's an ongoing thing she'll come in every day or every other day or whatever and we just leave it to her.'

…would she always be your first port of call?

'Oh yes.' CM1 Carer 1F

Confidence in the community matrons' abilities was enhanced when service users were aware of the extra training the role required and there was continuity. Many of the patients had received care from their community matron in her previous role as a district nurse and could describe how the role was a step on. A minority of respondents continued to call upon their GP if there were issues in their LTC management;

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however this was generally because their experience of the community matron was that she was likely to refer back to the GP and not prescribe herself. Hence, confidence in the community matrons' ability to provide effective CDM was increased when service users experienced the community matron practising autonomously.

The data also suggest a final distinct benefit of receiving care from a community matron; the enhancement of self-efficacy and psychological support:

> *'Oh she's been a great help, just her coming it gives you confidence, you can talk things over with her and there's nothing they can do for me, I know that and she has told me there's nothing at all, only that thing to keep me going on, so as I say it's somebody, when you're on your own you've got nobody to talk things over…' CM1 Patient 4M*

> *'I bring good communication and a relationship with the patient, because with the GP, he would just go in there and just have the job done and in 30 seconds, they're gone. Having us in there, we have the time, have a conversation with the patient, if they're having exacerbation, sometimes it's not about getting the medication, take it and just walk away. Sometimes they need somebody to sit down with them and talk, for example, sit with them, make them a cup of tea and then sit down and talk through it. By the time you've talked to them for half an hour, you can see the anxieties start going down, you start building that close relationship and it make your work so good.' CM2 Community matron 1*

Thus, the community matron was seen as providing CDM to the standard expected of a GP but also providing support in self-managing long- term conditions where there is no cure. Community matrons also suggested that a nursing background was vital for this role, as unlike other professions such as social care they were able to deal with both the medical and social care management of the service user:

> *'…the point is to reduce unnecessary hospital admissions, to make them comfortable in their own home, like bringing the hospital into their own home. So provide all the resources to make them feel better, but what I do is, to go to their houses, to review their care packages, because some people won't make them go to hospital, might not be the physical aspect of their illness, it could be the social. It could be their housing, their equipment, the carer, food and all kinds of things.' CM2 Community matron 2*

Because of the frailty of many of the patients there was less likely to be explicit strategies for involving service users in service development and evaluation. Any public involvement was more likely to be on an ad hoc basis via GP practices.

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5.4.5 The organisational whole system

The community matron model in both sites was explicitly placed within a whole system. In both sites community matrons worked alongside and interchangeably with other professionals including those from social care. In CM2 the data also suggested that health and social care sectors were becoming increasingly integrated. Community matrons from this site described how in the early days of the new service there were many problems with referrals to social care services including the need to complete lengthy forms and a significant waiting time until a social assessment was made. However, most of these problems were ironed out with obvious benefits for the service user:

> *'I've got a patient that lives alone, hasn't got no family, no food, the last time I went in there, I saw him eating a pack of crisps and he's got cancer. I was so shocked, he has nothing but bread, nothing in the house and then immediately I phoned the Social Services that I need a meals-on-wheels to start immediately. And that without them asking me to fill all these forms, he's got the service, there's the option that we start the service, essential we get food this afternoon and we can do the referral tomorrow.' CM2 Community matron 2*

This improvement in service was maintained by the social care manager attending regular meetings with the community matrons:

> ***'...****he comes out to monthly meetings and he was invited for the community matron…when we first started and we let him understand the kind of problem we're having with the Social Services because there's no need to do all this assessment…' CM2 Community matron 2*

In the CM2 site, case managers with a social care background but employed by the PCT worked alongside the community matrons. Patients who were deemed to have more social than health needs would be case managed by the case managers, leaving community matrons to manage patients with more health than social needs.

> *'If the needs were fairly complex then they would you know link in with a Case Manager so rather than sort of Social Services, you know because if there was sort of a lot of need that's sort of higher level than a Case Manager would be sort of involved. Between them they would decide who would actually case manage that patient because it seems strange having two sort of people involved. It would be based on whichever need is the greatest and that could change over time because initially you know when a Community Matron goes in if the overwhelming need is sort of medical because an exacerbation of a situation, no for a condition, then they would actually sort of case manage and bring in the Case Manager to sort of get services set up. Then the Case Manager may*

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> *do her bit and then hand over to Social Services or the Community Matron may find that she may manage to stabilise the patient quite quickly and then would hand over the case to the Case Manager if it was felt there was still a lot of social input.' CM2 Adult community nursing manager*

Community matrons also linked in with a number of condition specific nurse specialists either employed by the PCT or by local acute trusts. They would either use these specialists as a source of advice or refer patients onto if they required in-depth specialist input. Although all the community matrons had taken courses in condition management such as diabetes or COPD, they felt that this provided them with a generic base of knowledge and they still needed to access specialists for specific problems.

The data suggest that there were particular characteristics in the CM2 site that enabled whole system working. The PCT in CM2 was significantly involved in pilot projects, for example the community matron model had been initiated as a long- term condition pilot, bringing with it some funding from the Department of Health. The site has also just been accepted as an integrated care pilot project (Department of Health, 2008b) and was also a pilot site for the new Egton Medical Information Systems (EMIS) web system (see 5.4.6). Whilst being part of a pilot project had an initial benefit it also produced problems when the pilot was completed. It had been intended to have six community matrons in post recruited from the PCT's district nursing team leaders but only four were appointed. An external company, Serco Health, was used to provide the two extra community matrons and provide data and clinical support. When the project phase was completed a lack of decision about continuing funding resulted in Serco withdrawing its services and the four internal community matrons were required to reapply for their posts. Only three were reappointed with the fourth working in the role of community matron (band eight) but only being paid as a district nursing team leader (band seven). At the time of data collection there was a concurrent review of the district nursing service with a suggestion that the current 18 team leaders needed to be reduced to nine. The issue of funding disappearing at the end of a pilot project resulted in a sense of unease for all the staff.

Nevertheless, the community matrons in CM2 had invested enormous energy into making the pilot a success. There was initial resistance from many GPs who did not understand the role or potential benefits so much of the early work was around role dissemination and engagement of general practice:

> '*The community matrons are doing an amazing job at engaging with individual GPs who may have been more fairly dubious about the role, and have got some lovely anecdotal stories about us, you know GPs who initially wouldn't barely even talk to them about it, and then, now ringing them up and say "you've got to come and see this lady"', you know and this sort of thing, so that's really good to hear.'* CM2 Clinical supervisor

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However, despite all their effort there continued to be barriers to whole system working. One of the persistent problems was poor communication between the acute trusts and the community matron service:

> *'There have been occasions when I go to hospital and I have really fought with the staff, you know I said can you put my number on the computer beside this patient and phone me when this patient is coming home … but you still don't get that.' CM2 Community matron 3*

The data suggested that another barrier to effective working was concurrent problems with the district nursing staff levels, particularly high sickness rates in some areas:

> *'…when you deal with patients at that period of exacerbation you need to pass them over to the District Nurses to find out that you don't have the staff to pass that on so you end up doing what the District Nurses would be doing thereby not really utilising the Community Matrons time effectively.' CM2 Community matron 3*

Getting support and advice from GPs in a timely manner was also problematic for some community matrons, although this was not such an issue for those who were working with practices who had formerly known them. All the community matrons in CM2 were former district nursing team leaders and although employed by the PCT would have been attached in that role to a specific GP practice. In contrast, as a community matron they were covering a number of GP practices but enjoyed particularly good communication with the practice they had been attached to as a district nurse.

There was some evidence that community matrons were helping patients to navigate the whole system, either vicariously by organizing other services for them, or by information giving to the service user or relative:

> *'I think I tend to explain, I go beyond anything else you know because I mean if I have the knowledge why not give it to them because I believe that if you give them the knowledge it will help them to manage their condition much better, you know, so I tend to encourage them to take control of their condition and the only way to do that is to give them the knowledge, you know, and that is what most of them have… even the family they keep calling me and say "oh can you explain to me why this is happening, why this is happening?" And if I don't have that information then I always say to them "I don't have this information now but I will get back to you".' CM2 Community matron 3*

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5.4.6 The data system

Out of the case studies within this project, the community matrons had the most explicit data system set up as their role commenced. The main purpose of the data system was to case find and to track hospital admissions. In the early days of the LTCs project in CM2, the data system had been organised and provided by Serco, however their rapid withdrawal from the project had left the case study site with a system that was complex and difficult to adapt for local need. Similarly, in CM1 site there was also problems with the data system as the merger of three PCTs resulted in significant changes to the IT system. One system (CHIPS) was transferring to a new system ISOFT (a specialist health information technology provider). The changeover resulted in increased pressure on the IT staff which undoubtedly impacted on the site's initial willingness to distribute the survey and participate in the study. In CM1 data were routinely collected on age, gender, predominating condition, polypharmacy, outcomes, BP and FEV1 (Forced Expiratory volume in one second) measurements.

The focus on data collection to track hospital admissions proved problematic for many community matrons. At the consensus conference (4.2.4), there had been concern from participants about the sole reliance on this as a measure of the community matron's effectiveness and indeed there was evidence suggesting this was the case in CM2:

> *'I haven't got the data here in front of me but you know one thing we did have to do is capture you know, avoid, hospital avoidance and it's really made a difference to you know, sort of visits to the hospital with following sort of cases and looking at… I don't think we've costed sort of bed days as such but you know we can actually look at you know, the individual cases and we've captured that, you know how it's reduced the sort of visits to GP practices, to the hospital.' CM2 Adult community nursing manager*

However, within CM2 site there was the potential problem of community matrons being unable to take direct referrals from GPs which would have speeded up the rate of response:

> *'….most of our referrals for the community matron and the district nurses go through to adult health and then you've got the single point of access…they are trying to bring everything together so to avoid that confusion…I mean with all this confusion we now say to the GP, we give them our email, why not send this patient direct to us….But again the Trust don't want that because they want to capture all the new referrals.' CM2 Community matron 3*

The problems with the data system were also exemplified in CM2 by the lack of administration support resulting in community matron's having to deal with a large amount of paperwork;

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> *'…the paperwork is horrendous and we have a laptop that doesn't help very much, sometimes the laptop will…sometimes you cannot get signal, the laptop don't work.' CM2 Community matron 1*

> *'…currently at the moment the community matrons have a laptop with 3G connectivity, but they have to obviously go through the 3G gateway to connect into (PCT) which makes it a very time consuming process, and they're not utilising those in the patients home as much as we would like them to be able to, but for good reasons.' CM2 Adult community nursing manager*

Apart from connectivity problems, community matrons also reported that many patients did not like laptops to be used in their home with concerns about costs of electricity. There was a continued reliance on paper sourced data, with folders kept in patients' homes in which all professionals had a section to complete on each visit. Patients and relatives were discouraged from contributing to these notes and there was a separate 'conversation book' used for written communication between the community matrons and any informal carers.

Issues with accessing systems used by the GPs was also problematic with some community matrons in CM2 reporting that they spent much time in visiting several GP practices to communicate:

> *'…then another thing I can say the challenge is the time we spent running around from one GP practice to another and you know trying to input, at least for the GP to know what you've been doing officially with it to prescribe medication, you need to let them know so running from one GP to another it takes a lot of time.' CM2 Community matron 3*

One respondent (district nursi ng team leader) also pointed out that a major challenge for many of the nurses was a lack of IT skills:

> *'…another handicap I have is that my IT skills are below standard' CM2 District nurse*

Despite all these issues, at the time of data collection it appeared that many would be resolved by being part of the EMIS web project. Once set up the majority of GP practices, community matrons, community nursing and the PCT would be using a single system. The EMIS web would also include a "flagging up" system for the emergency department and out of hour's service that the patient was being case managed. There were reported delays in the implementation of the pilot but all staff were receiving training on how to use it and it was seen as a potential solution to many issues:

> *'…it should be a significant advantage anyway but also obviously the capability of having that single patient record is a huge advantage and will, you know, hopefully will reduce sort of clinical*

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governance risks significantly.' CM2 Adult community nursing manager

There were also plans to combine data from the community matrons and social care which was in line with integrated care pilot:

'I'd like you (social care manager) *to collect some combined data, you know because obviously I've said, you know the Community Matrons aren't successful if they work in isolation, you know their success is based on all this integration work that goes on and you know, how it's impacted on them and perhaps if we can look at, you know a sort of number of patients that they've been involved with the Community Matrons and we've put that on the agenda for our next meeting to look at how we can connect some joint data.'* CM2 *Adult community nursing manager*

Thus the data system in CM2 was constantly evolving and enhanced by pilot funding. Many challenges were being addressed but more were likely to arise as in all new systems and ways of working.

5.4.7 The causal system

The model in both sites was triggered by a top-down initiative from the Department of Health. As described in 5.4.1, demographic and epidemiological changes with the resulting increased demand on health and social care resources challenged policy makers to look for new ways of meeting the needs of service users and managing costs. It was clear that previous community service provision for people with multiple complex physical needs was inadequate, resulting in a small percentage of the population placing major demands on the health service by frequent unplanned hospital admissions (Dr Foster Intelligence, 2006). Prior to the advent of the community matron model, most community based health care for people with LTCs was provided by GPs and district nurses (Audit Commission, 1999), however there has been persistent concerns that the district nursing service was not having an impact on reducing health service demand and were top heavy with senior nurses who were not utilising their skills appropriately (National Health Service Management Executive, 1992):

'…we knew that district nurses were task-focused, who didn't proactively case find and case manage, who didn't keep people out of hospitals, so they needed someone highly skilled to do that…' CM2 Community matron 2

Hence, alongside the introduction of the community matron in each site there was an on-going review of the district nursing service. In site CM1 this involved the whole of the community workforce in a 'productivity' project. This appeared to be the final event in a long chain of

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consequences from the PCT amalgamations that made potential respondents reluctant to take part in the research project. In the CM2 site district nursing was undergoing a 'transformation' project. In response to the local strategic aim of reducing the number of district nursing team leaders by half, potential community matrons had been selected from existing team leaders so all were internal candidates with a district nursing background. In addition, alongside the introduction of community matrons, district nursing team leaders were being offered courses to extend their skills in LTCs. For example, a number had completed the independent prescribing course and a range of courses on specific LTCs.

As all nurse respondents were either current or past district nurses they were asked to describe how the community matron role differed from that of a district nurse. Differences are illustrated in Table 14

Table 14 Differences in the community matron and district nurse role

Community Matron	District Nurse
Proactive	Reactive
case finding	responding to referral
Trying to prevent a crisis	Task orientated
Advanced clinical skills autonomous practice	Changes to treatment refer back to GP

However, the data suggested that it was often the organisational structures that shaped practice in this way. For example, community matrons had a maximum caseload of 50 whilst the district nurses had caseloads of well over 100 patients and although community matrons and district nurses appeared to communicate well, there was often an undercurrent of resentment over the time community matrons had to spend with their patients:

> *'The only difference in what I do and what the community matron does is the physical assessment and the fact they have more time to input into long-term conditions and I haven't…' CM2 District nurse*

> '*…suddenly you know, Community Matron comes along and saying they're going to be the experts around long-term conditions, they* (district nurses) *found that very difficult to understand, you know,*

> *and we did for a while as well, you know, we were just being told you know, these roles had to happen and we couldn't at first and then sort of see the difference between a Team Leader and what was going to be the Community Matron role.' CM2 Adult community nursing manager*

The blurring of boundaries between community matrons and district nurses was identified by management:

> *'…very difficult to say what the differentials being a Band six, a Band seven, you know sort of Band eight, you know sort of Community Matrons… our Community Matrons came out as Band 8A. And considering we were developing our Band sevens* (district nurse team leaders)*very much around CDM and we expected you know within that role, that they would do independent prescribing plus you know the physical first contact assessment course. And they were already developing skills around doing sort of home and diabetic checks and respiratory, as I said, you know earlier on, around respiratory training and doing spirometry.' CM2 Adult community nursing manager*

District nurses who had received extra clinical skills training clearly revelled in the autonomy:

> *'The joy is not having to call the GP if there is a UTI* (urinary tract infection), *be able to start the treatment and not having to wait…' CM2 District nurse*

However, equally there was frustration about not being able to take these skills further:

> *'I actually want to be prescribing for my COPD patients, my LTC patients, but my hands are tied at the minute because there's supposed to be a GP….but because there are loads of issues and we're going through a lot of locums and the GPs just come and go…there is no lead GP for prescribing, I need one of them to supervise me, someone I can sit and discuss with in the beginning…' CM2 District nurse*

Against this backdrop of an almost seismic shift in the way community nursing was delivered with consequent anxiety of existing staff, community matrons also needed to articulate and market their role which was an unknown quantity to many stakeholders, not least GPs:

> *'…there was definitely some barriers within General Practice, as in, you know, 'what are those people doing' and 'why do we need them'. Some of that I think came from the fact that it was a political imperative to have community matrons and there's slightly*

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> *a feeling of you know, we should be able to determine the needs locally.'* CM2 Clinical supervisor

As described earlier, the community matrons invested great time and effort into role dissemination and the data suggest that the process was enabled by being already known to local GP practices and social care:

> *'I mean our four community matrons that we have in post at the moment have worked incredibly hard and had to sort of overcome a lot of barriers and I think that's probably a process that in some respects we went through in General Practice a few years ago with the introduction of nurse practitioners etc, a similar sort of process in that respect.'* CM2 Clinical supervisor

The data suggested that in the perception of the community matrons, GPs started to embrace the role once they began to see cost savings and the bonus of having a professional to pass on the 'problem' patient. However, there was some reporting by community matrons in CM2 of role duplication, particularly with community based respiratory nurse specialists.

Community matrons also undertook other activities to embed themselves within the whole system. This included ensuring they 'spoke the language' and would make great effort in using medical terminology when communicating with GPs:

> *'I'm always reading, so I read about it before I meet with the GPs, I always do the preparation…. So at least they're (*GP) *more interested ;"mmm, she knows what she's talking about"…' CM2 Community matron 2*

In addition, they clearly articulated a public health aspect to their role. Diabetes has been identified as one of the most significant health challenges the PCT faces and so community matrons participated in open days at GP surgeries, talking to families and undertaking diagnostic processes.

Finally, the data suggested that the community matrons in CM2 had developed a strong support network amongst themselves, meeting every week as a facilitated action learning process. In these sessions they discuss issues and invite specialists to speak on selected topics. The support extended beyond these meetings, for example the sharing of expertise on a day to day basis:

> *'We tend to do different courses and probably where your preferences lie but there are certain things that everyone has to do like the physical assessment and non-medical prescribing.'*
>
> And do you link in so if someone else has done a COPD course might you talk to them about it?
>
> *'Oh definitely we do, yes.' CM2 Community matron 3*

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Considering the difficulties the community matrons had in contacting a GP for advice (described earlier), they relied heavily on each other to provide confirmation of their decision making if they felt unsure:

> *'… I just went to see a patient and I wasn't sure if I should get the ambulance. I know that our role is not to let the patient go to hospital but I have to, so this patient she doesn't look right and she just came out of hospital about two weeks ago or something I waited, last week I did blood test on her, run all the things and nothing has improved and the doctor started her on diuretics but I mean I was sitting there looking at her which I noticed the changes, it's not the patient you know, I usually come to see. She is getting weaker …there are all those things that can cause that, you know when they are anaemic and things like that. But when I check her lungs there was no, um enough entering to the lungs so I had to speak to one of my colleagues, I say this is what…. I explain everything to her. But said to her "this is what I'm thinking of, what do you think?" And she said "the best thing you can do is to get ambulance for this lady and take her into hospital instead of her staying there".' CM2 Community matron 3*

Mobile telephone contact between community matrons in CM2 was frequent, particularly as they were located in different bases. However, co-location with other professionals such as the district nurses or social services was seen as a great enabler of whole system working.

In summary, the community matron role had not evolved in the same way as the other models within this research. In contrast this model had been implemented in a top-down approach with associated problems common to quick and imposed changes. In both sites the implementation came at a time when the existing community nursing workforce was under review and change. The model has been championed by the community matrons themselves, and the pressure to deliver observable results such as hospital admission reductions has been immense. The model lies within a whole system comprising of a causal system with a range of competing forces. However, as illustrated in figure 5, the data system and organisational whole system enable whole system working which is evidenced in the user experience.

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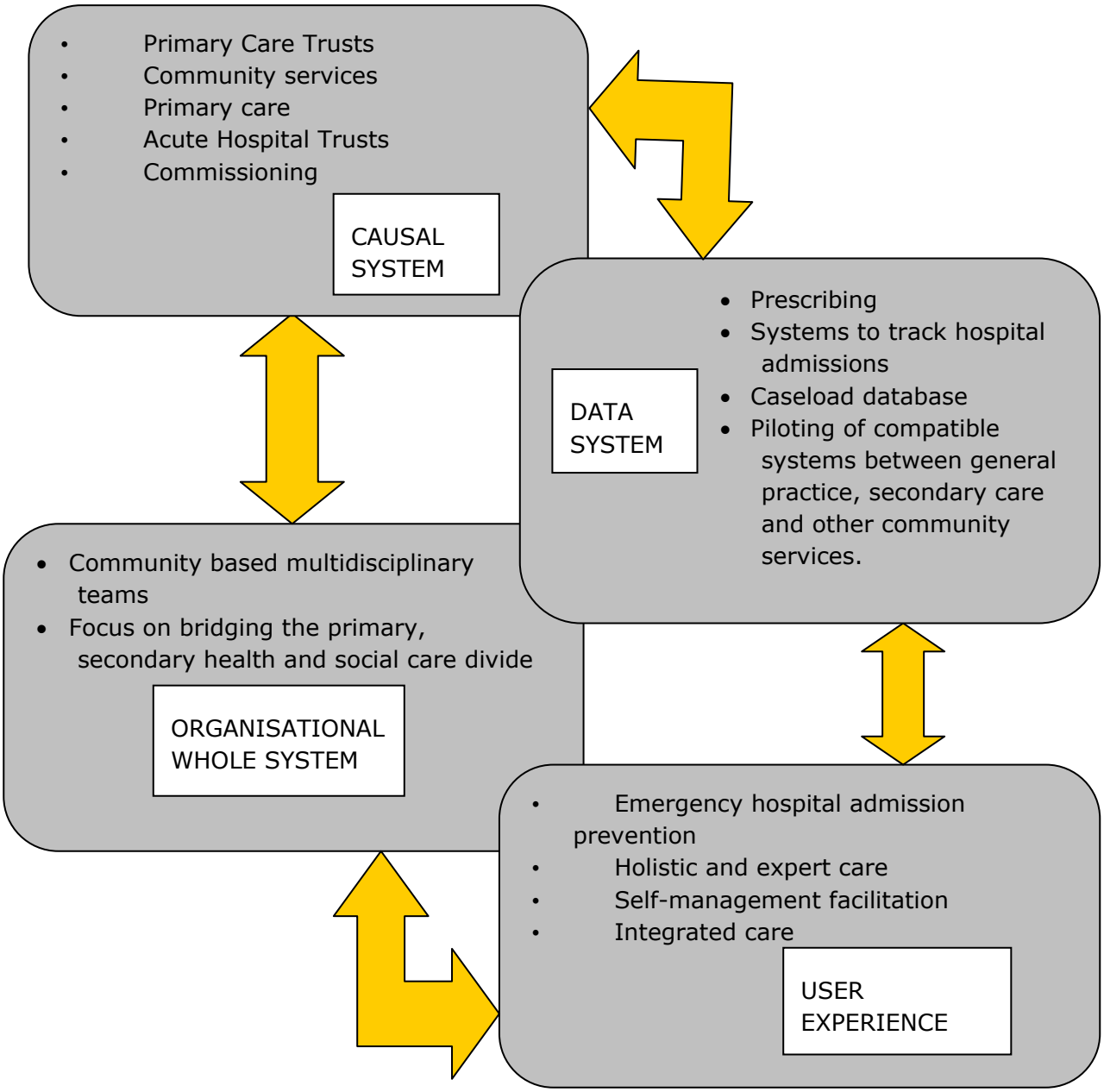
Figure 5 Community Matron model and whole systems framework



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5.4.8 Summary

An in-depth description of the political and social context of the seven case studies has been presented within this section.

The focus of the Public Health case study was the PCT's Schools Asthma Strategy led by the asthma coordinator who was a school nurse. The relatively small sample of young people and their parents indicated confidence in asthma self-management but did not provide any evidence of awareness of the nurse coordinated asthma strategy. As a coherent strategy the Public Health model was effective in spanning the school/health boundary but faced more barriers in primary care. Current data systems were also limited in their interface with general practice. The asthma coordinator was central in providing leadership and vision to the strategy, but there was dependency on this individual nurse to drive the strategy forward with little succession planning.

Two case study sites provided the locations for the Primary Care Nurse model, one focused on nurse-run clinics for type 2 diabetes, the other a skill mixed team of primary care nurses running a range of chronic disease clinics. The service user data indicated that patients were using the disease management clinics set up by GP practices and found them helpful in monitoring and managing their disease, although they had restricted open access to clinics and nurses. Many patients had co-morbidities and in many cases the clinics they attended did not coincide with what the patient considered to be their main health problem. Data systems were still organised around the prevalence of disease in a given population and not around the patient experience of disease, and patients with more than one chronic disease were often counted on more than one disease register. The relationship between primary and secondary care remains largely intact. GP practices are providing routine management of single chronic diseases, and care is geared to meet the needs of the uncomplicated stable patient. Patients who have experienced secondary care tend to continue to access it when offered as they perceive that secondary care (including nurse run secondary care) is more informed by specialist knowledge.

In the two case study sites demonstrating the nurse specialist model (an epilepsy nurse specialist and a skill mixed team of diabetes nurse specialists), service users and carers particularly valued the psychological support offered when they felt vulnerable such as at diagnosis or periods of instability. There was confidence in the nurse specialist's expertise and skills in disease management. In one site this confidence and the organisational system resulted in service users regarding the nurse as the medical expert. However, in the other site service users expressed an overall preference for their disease management to be led by a doctor although this was counterbalanced by the greater accessibility and speed of response by the nurse, and an acknowledgement that this preference may be shaped by what was familiar. The model continued to span both primary and secondary health care sectors and this was proactively promoted by the nurse specialists', often against prevailing changes in

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commissioning. Data systems varied greatly between the sites and appeared based on the need to closely track physiological outcomes as part of a multidisciplinary team approach. The model follows a template drawn from medicine and sustainability is significantly dependent on the championship and protectionism offered by senior medical clinicians.

The limited data we collected on the community matron model in two sites suggest that service user satisfaction with this model was high, particularly with the emphasis on hospital admission prevention, meeting medical, nursing and psychosocial needs, and providing continuity of care. The community matron model was explicitly placed within a whole system. In both sites community matrons worked alongside and interchangeably with other professionals including those from social care, and had the most explicit data system set up as their role commenced. The main purpose of the data system was to case find and to track hospital admissions, however a lack of administration support resulted in community matron's dealing with a large amount of paperwork. This model had been implemented in a top-down approach with associated problems common to quick and imposed changes. In both sites the implementation came at a time when the existing community nursing workforce was under review and change. The model has been championed by the community matrons themselves, and the pressure to deliver observable results such as hospital admission reductions has been significant.

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6 Survey data

As described in section 2.1 of this report, one of the aims of the project was to measure the impact of the assessed models represented by the case studies, on outcomes for service users. For the adult sites (primary care nursing, specialist nursing and community matron models) we collected generic measures through the HODaR patient questionnaire. The analysis was undertaken in collaboration with CRC Ltd. Cardiff and the findings are presented in 6.2. The survey data were also drawn upon to inform the economic evaluation, however as HODaR do not hold data on children we were unable to perform an economic evaluation of the public health model. The costing methods are detailed in section 7, and in addition to the survey results also relied on the nurse respondents' self-reported audit of activities. Within the public health model we administered an adapted version of the Health Behaviour of School Aged Children which incorporated measures of self-efficacy drawn from the Children's Arthritis Self-Efficacy Scale (CASE) (Barlow *et al,* 2001) (appendix21).

6.1 Survey findings from the public health model site

The purpose of the survey in the public health (PH) model site was to both provide a broader analysis of the role of school health advisors in the wider education and awareness of asthma in this PCT from the perspective of young people and to provide a basis for assessing the typicality of these young people in comparison to national data on asthma and the Health Behaviour of School Aged Children (HBSC) survey (Inchley *et al*, 2007). The survey instrument can be found in appendix 11.

The sample for this survey is described in 2.5.5 and Appendix 15. A total of 328 young people aged 11 to 16 were invited to respond, 75 completed the survey, a response rate of 23 percent (table 15).

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Table 15. Number of young people who responded to the survey by school year.

School year	Number sent out	Number responding	Response rate
7	65	14	22%
8	54	18	33%
9	58	15	26%
10	82	14	17%
11	69	14	20%
Total	328	75	23%

It is recognised that the response rate is relatively low in comparison with the HBSC survey which uses a quota sampling strategy for each age group in each participating country (total of 4500 for England in 2005/6). Our response rate was limited by the resources available and the research governance requirements that limited direct contact between the researchers and the schools involved. We therefore had to rely on the availability and time constraints of the Children's Service Department in sending out questionnaires and consent forms. Nonetheless, while recognising the limitations of our sample, the findings are of interest. However, due to the small cell sizes it was not possible to test relationships between variables within our survey in any meaningful way.

6.1.1 Prevalence of asthma

Asthma is prevalent in 10 to 15 percent of all school-aged children in the PH site. This is based on census figures, lifestyle survey[8] data and school asthma register numbers. Comparison with national trends is not unproblematic, as discussed by Anderson *et al* (2004). Their report on national trends in asthma prevalence found that reports vary in their use of asthma symptoms, severity measures and that there are important gaps in the asthma trends database. A series of surveys conducted between 1995 and 2002 of 11 to 14 year olds by Anderson *et al* (2004) using the International Allergies and Asthma in Childhood survey reported a lifetime prevalence of 25 percent in south-east England, suggesting that

[8] The full reference has not been given as this would identify the case study site location.

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the prevalence in our selected site was considerably lower. It is feasible that many young people in our PH site with asthma symptoms are not being identified for the purposes of the asthma register, either because their symptoms are not severe enough or they are not recorded adequately.

Using service utilisation as a measure of asthma severity, we found that 10 young people (14 percent of respondents) had visited their GP for their asthma in the last 6 weeks and that the vast majority (96 percent, 4 percent missing data) had not been admitted to hospital for their asthma in the last 6 months. The Office for National Statistics data for 2004 (Gupta and Strachan, 2004) show that both GP consultations and hospital admissions for children aged between 5 and 14 have fallen since the late 1990's to around 50 per 100,000 GP consultations per week and about 18 per 10,000 hospital admissions annually in 2000.

6.1.2 Population data

Most of the schools in our sample had a higher proportion of pupils achieving 5 GCSEs at grades A* to C (including English & Maths) in 2008 than the average of 48 percent nationally (Department for Children, Schools and Families, 2008). This meant that almost 90 percent of young people who replied to the survey were from higher achieving schools than the national average. This may have influenced the responses through selection bias.

The majority, 61 percent, of our respondents were male. This is in line with findings from Asthma UK, which says 'Asthma is more common among boys than girls and over the age of 14, the prevalence reverses and asthma is higher among women than men. This may be because boys can grow out of the condition and girls can develop asthma symptoms around puberty' (Asthma UK, 2009).

A high proportion of the pupils were born in October (19 percent), which is unexplained as ONS birth statistics for all births do not show a peak in this month (table 16). However, an early study by Anderson *et al* (1981) did conclude that there is likely to be a seasonal effect of birth month and prevalence of respiratory symptoms in children, indicating that May to November births were most likely to be associated with asthma. They also conclude that the mechanisms for this remain obscure. We considered this to be an interesting artefact finding from the survey as there appears to be little published work on this.

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Table 16. A comparison of the proportion of live births in England and Wales by month and birth month of PH site pupils.

Births	Birth month												All births
	J	F	M	A	M	J	J	A	S	O	N	D	
ONS live births % E&W	8	7	8	8	9	8	9	9	9	9	8	8	100% n=690,000
PH site %	5	11	5	9	9	4	11	8	5	19	7	7	100% n=75

In our survey, 8 percent of the young people were non-white, which is a similar proportion to the 2001 census figures for the PH site as a whole.

6.1.3 Health and Lifestyle

Our survey was designed to ask respondents to tell us about their asthma and also about their general health and lifestyle. These latter questions were identical to those used in the HBSC survey for benchmarking purposes. For the purposes of this discussion we have used the data for the 13 year olds (year 9) from the HBSC as our benchmark in most cases as this was our median age.

Smoking and alcohol

Since our sample was drawn from the asthma register it was not surprising that 93 percent did not smoke. Eighty-eight percent claimed they had never smoked while a very small proportion (5 percent) said they smoked every day. The HBSC survey for 2006 found that 8 percent of 13 year olds smoke daily and 22 percent of 15 year olds, with a higher percentage of girls than boys smoking daily. Our sample was too small to make a distinction between girls and boys but overall suggests that young people with asthma symptoms are less likely to smoke than young people in general.

The majority of young people in our survey never drank alcohol (59 percent). However, 5 percent drank alcohol once a week and 4 percent also said they drank alcohol more than two days per week. This compares very differently to the HBSC survey where 16 percent of 11 year olds, 37 percent of 13 year olds and 79 percent of 15 year olds report drinking alcohol daily. This is worth further exploration, but is suggestive that

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asthma symptoms might be protective against other health risk behaviours.

Physical activity

Over a typical week, almost a third (29 percent) of our respondents were physically active for total of at least 60 minutes a day, every day. Overall boys (20 percent) were much more active than girls (9 percent) when reporting physical activity every day. This is in line with both national and international data from the HBSC survey that show younger children and boys are more active than girls and older children. The data for England showed that 14 percent of 13 year-old girls and 24 percent of 13 year-old boys are physically active every day. Our slightly lower proportions of activity might reflect their asthma symptoms.

Diet

Fruit was eaten at least once a day by half of our respondents (51 percent). Vegetables were eaten at least once a day by nearly half (45 percent) of the pupils. Just over one third (36 percent) ate chocolate or sweets at least daily and about one fifth (21 percent) drank coke/soft drinks containing sugar daily. This compares well with the HBSC survey, reporting that 46 percent of 13 year-olds eat fruit daily and that 18 percent of girls and 26 percent of boys drink sugary soft drinks daily.

We asked young people to report their weight and height. Weight ranged from 27 to 83 kg. and height from 1.4 to 1.9m. The mean body mass index (BMI) of the 54 young people who gave their weight and height was 20. Their BMI ranged from 14 to 28. Of our respondents, 7 percent were happy with their weight, 72 percent felt they were unhappy with their weight and should be dieting while 15 percent felt they should put weight on and 7 percent of our sample were actively trying to lose weight. In comparison with the HBSC survey, our respondents are much less likely to be dieting. In the HBSC survey 20 percent of 13 year-old girls and 9 percent of 13 year-old boys were dieting or doing something else to lose weight. There was no relationship in our survey between frequency of food/drink consumed and the weight/height of the individual.

6.1.4 Asthma symptoms

In our survey, 55 percent of the young people reported that they were rarely or never breathless, while 16 percent were breathless every month and 9 percent breathless every day. There was no relationship between frequency of exercise and frequency of breathlessness.

One in 20 were wheezy daily and less than half said they were rarely or never wheezy during the previous six months. Just over a tenth did not have an inhaler. It was reported that 15 percent forgot to take their medicines/inhalers most or all of the time. When asked 'Do you feel the tablets/medicines/inhalers are doing you good?' 15 percent replied 'none of the time' or 'a little of the time'. Nearly 60 percent stopped using their inhaler if they felt well.

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When asked to score their 'best possible life' out of 10, the mean scores increased overall as the frequency of breathlessness decreased (Table 17).

Table 17. Mean best possible life score by frequency of breathlessness

Frequency of breathlessness	Mean best possible life score	N Std	deviation
about every day	6.7	7	1.4
more than once a week	6.5	8	3.2
about every week	7.0	6	1.7
about every month or less	8.2	53	1.7
Total	7.8	74	2.0

Not surprisingly, this suggests that frequency of breathlessness as a result of asthma does have an impact on the quality of life of young people. However, there was no relationship between frequency of breathlessness and number of times the young person visited a nurse and the same was true for visits to a family doctor.

The majority of our respondents had not had any time off school in the previous six weeks because of their asthma and for the most part it did not affect their normal activities. Only two young people said that during the last six weeks their asthma stopped them doing everyday activities and/or daily routines. A majority of 90 percent felt they could control their asthma at school.

6.1.5 Mood and general health

Almost 40 percent said they had felt low at least once during the previous six months. Equally, 53 percent never felt nervous while almost one third (30 percent) reported feeling nervous about once a month. Perhaps reflective of their age, a higher proportion (36 percent) felt irritable or bad tempered once a month. However, 88 percent said they felt very or quite happy with their life at the moment and a similar proportion said they were in excellent or good health, while just over a tenth (11 percent) reported their general health to be fair or poor. This compares with 21 percent of girls and 19 percent of 13 year-old boys from the HBSC survey. When asked how they would score from 1 to 10 (high) on the best possible life the majority (55 percent) scored 8 or 9. Compared with the HBSC survey, an average of 88 percent for both sexes scored 6 or above while 87 percent of boys and 81 percent of girls in the HBSC survey scored

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6 or above. This suggests that the case study population perceived they had a higher quality of life than school aged children nationally. Speculatively, this might be explained by the presence of asthma itself, that our sample of young people received more attention and were possibly more aware of their health than the wider population and also by the higher family affluence scores (see 6.1.6 below).

Almost 80 percent had never been bullied within the last two months but 4 percent reported being bullied once or twice in the last two months and 12 percent said they had been bullied several times a week. Girls were slightly more likely to report being bullied than boys. The cell sizes were too small to observe any relationships between bullying and other health or mood related variables.

Girls reported higher frequencies of headaches, stomach-ache, feeling low and feeling dizzy and there was a statistically significant relationship between gender and frequency of these ailments. One third of the young people had other conditions as well as asthma e.g. eczema, allergies.

Two thirds of those surveyed found it very easy or easy to talk to a doctor about things that really bothered them. A similar proportion said the same about talking to a nurse.

6.1.6 Family affluence

The HBSC survey measures family affluence by collecting data on family computer and car ownership, number of family holidays per year, and whether a child has their own bedroom. In our survey, only two respondents did not own a computer in the family and in over one fifth (21 percent) there were more than two computers in the family. The majority of young people had their own bedrooms (84 percent). Over two thirds (68 percent) owned two or more cars and almost two-thirds (65 percent) had at least two family holidays per year. While it would appear that our sample scored relatively highly in terms of family affluence, the HBSC survey showed that 60 percent of English children score highly and 31 percent medium, with England being the third highest scoring country after Iceland and Norway. Three quarters of our sample lived with both their mother and father.

A quarter of our sample were not involved in any clubs or activities.

6.1.7 Confidence in coping with asthma

Within the survey, we asked young people a series of questions that considered their confidence in managing a range of circumstances in relation to their asthma (appendix 21).

The questions, adapted from the CASE tool (Barlow *et al,* 2001), were designed to obtain a sense of the young person's self-efficacy in relation to their asthma symptoms.

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On most of the variables two thirds or more of the respondents scored very sure indicating a high level of confidence in coping with asthma. In two areas, PE at school and being annoyed or fed up, less than 60 percent scored very sure, but most others were quite sure. A larger sample would have enabled us to compare the scores from this aspect of the survey with other variables such as breathlessness, use of inhalers, family affluence and bullying.

6.1.8 Summary

In summary, the findings from the survey of young people with asthma from the PH model show that in many ways these young people were not dissimilar to young people from the rest of England who have taken part in the HBSC survey. Their affluence, lifestyles, mood and general health perceptions are comparable. Obviously our sample differed in that they were known to have asthma symptoms and in this respect there were some noticeable differences from the general population of young people. In particular, our sample were less likely to smoke, drink alcohol and take physical activity every day. They were also from more affluent families than the HBSC sample and perceived themselves to have a better life score. While we could not show any statistical association between these variables and breathlessness or wheeziness (apart from life score), this is likely to be due to the limited sample size rather than lack of relationship per se.

Overall, the young people in this survey appear to be confident in managing their asthma both medically and under various social circumstances. They appear to have a positive outlook on their lives and are achieving well at school. Their reported use of health services appears to be similar to national data. While being cautious of our findings in relation to the response rate, we would tentatively suggest that in line with our qualitative findings, the public health model is supporting these young people with asthma well in relation to their health and lifestyle, service use and confidence in managing asthma. We would describe this as the 'invisible' nature of public health in that individuals are not necessarily aware of services such as the asthma co-ordinator in their everyday experience, but nonetheless the young people and their parents did provide both qualitative and quantitative evidence of good asthma management. This survey should, however, be regarded as a pilot study and poses questions for a much wider survey of young people with asthma in England.

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6.2 Adult case study sites survey findings[9]

Questionnaires were sent out by post to patients with a range of long-term conditions from within the adult case study sites. The nurse caseloads at each site varied in size and in the way they were recorded with some sites just maintaining paper records. Advice from HODaR suggested a sample of about 300 patients per caseload were needed. In PCN2 the caseload far exceeded this and so a random sampling strategy was adopted. In PCN1 and NS1 the caseload fell short of this so all patients were sampled. In NS2 just patients on the DESMOND and DAFNE programmes were sampled as the city wide approach of which the nurse specialist was a part made it difficult to identify a specific nurse specialist caseload. The nurse consultant was however, instrumental in setting up and running the DESMOND and DAPHNE programmes and therefore after extensive consultation it was decided that these were the most representative group of patients to sample from. The patients were accessed via the clinicians involved in their model of CDM as follows:

PCN1: all adults on caseload were sent surveys.[10]
PCN2: every 4th adult patient within disease group were sent surveys.
NS1: all adult caseload excluding specific patients with Learning Difficulties[11]
NS2: all patients on DESMOND and DAFNE programmes and further sample from the review database

CM1: surveys were handed out by Community Matrons[12]

The patients were matched with HODaR patients on age (+/- 5 years), sex and main morbidities (COPD, diabetes and epilepsy). Differences in the sampling strategy in our survey were a methodological limitation but were constrained by the total numbers of patients on the nurse caseload.

The questionnaires were printed by the Cardiff Research Consortium (CRC), sent out by the individual sites, and returned by pre-paid envelopes directly to the researchers. All patient data were anonymised by the use of a bar-code identifier that linked the questionnaire to the patient. Thus researchers were not aware of the patient identity until the consent forms were completed and returned. Reminders were sent out once, via the clinicians in each site, to all patients who had not responded. Data collection took place between November 2007 and May 2008. Of those sampled for the survey, a further sub-sample agreed to be interviewed as part of the qualitative study of the patient and carer experience (Appendix 14).

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[9] With thanks to Rhys D. Pockett and Chris Morgan, CHKS Health Economics Unit, Cardiff Research Consortium Ltd.

[10] PCN1 and 2= Primary Health Care models

[11] NS1 and 2 = Nurse Specialist models

[12] CM1= Community Matron model

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The purpose of the survey was to collect evidence on the health status, quality of life, self-efficacy and health service utilisation of patients with long-term conditions who were receiving nursing intervention from a selection of models of CDM that were identified through the consensus methods discussed in the methods section (section 2). Data were analysed to provide a *description* of the total sample of patients, to identify differences between models and to benchmark our sample against a matched sample of patients from the HoDAR database. The sample sizes and response rates were generally considered too low to carry out inferential statistical analysis. However, some regression analyses were also undertaken to investigate the relationship between variables.

Health status was measured using patient self-report on a range of variables and clinical data were also used for patients from NS2. Clinical data were not made available from the other sites, or were too limited to be useable.

Quality of life was measured using EQ-5D (Szende, 2007)

Health outcomes: SF12 (Stewart and Ware, 1991).

Self-efficacy was measured using the Generalised Self –efficacy tool (Stanford Patient Education Research Center, 2001).

Health Service Utilisation was based on the HoDaR questionnaire with some additional questions for the purpose of this study.

The full survey instrument can be seen in appendix 10.

Piloting and validation were not deemed necessary as the instruments were well tested in the literature and have been consistently used by the CRC Ltd. which has a good track record of peer reviewed publications.

6.2.1 Results

Response rate

There were a total of 347 responses across all sites. One reminder was sent out but this was also limited by the reliance of the research team on NHS administrators and practitioners as we were bound by ethics not to know the personal details of patients. Response rate by site is shown in table 18.

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Table 18. Response rate by site

Site	Responses	Dispatched	Response rate
PCN1	64	312	20.5%
PCN2	75	300	25.0%
NS1	101	395	25.6%
CM1	34	-	-
NS2	73	300	24.3%
Total	347	-	-

The disappointing response rate does pose limitations on the study findings. In CM1 only 34 patients were recruited due the extreme age and frailty of most of the patients on the caseload and we not given information from the site on how many surveys had been distributed, so were unable to calculate the response rate. In view of the poor response rate it was agreed with the CRC that a second time point survey would not be distributed. This further limited the level of analysis and interpretation that could be applied.

Demographics

Age or year of birth was recorded for all patients (mean age 58.2; sd 17.6). There were 175 males (mean age 61.3; sd 16.2) and 159 females (mean age 54.1; sd 18.6). Gender was missing for 13 (3.7 percent) cases (mean age 66.8; sd 14.5).

Figure 6 shows the age and gender profile of patients. Figure 7 shows the age and gender of patients as a proportion of responders by site.

Patients at the younger end of the spectrum tended to be within NS1, a model that specialised in epilepsy management and not therefore as age-related as other conditions.

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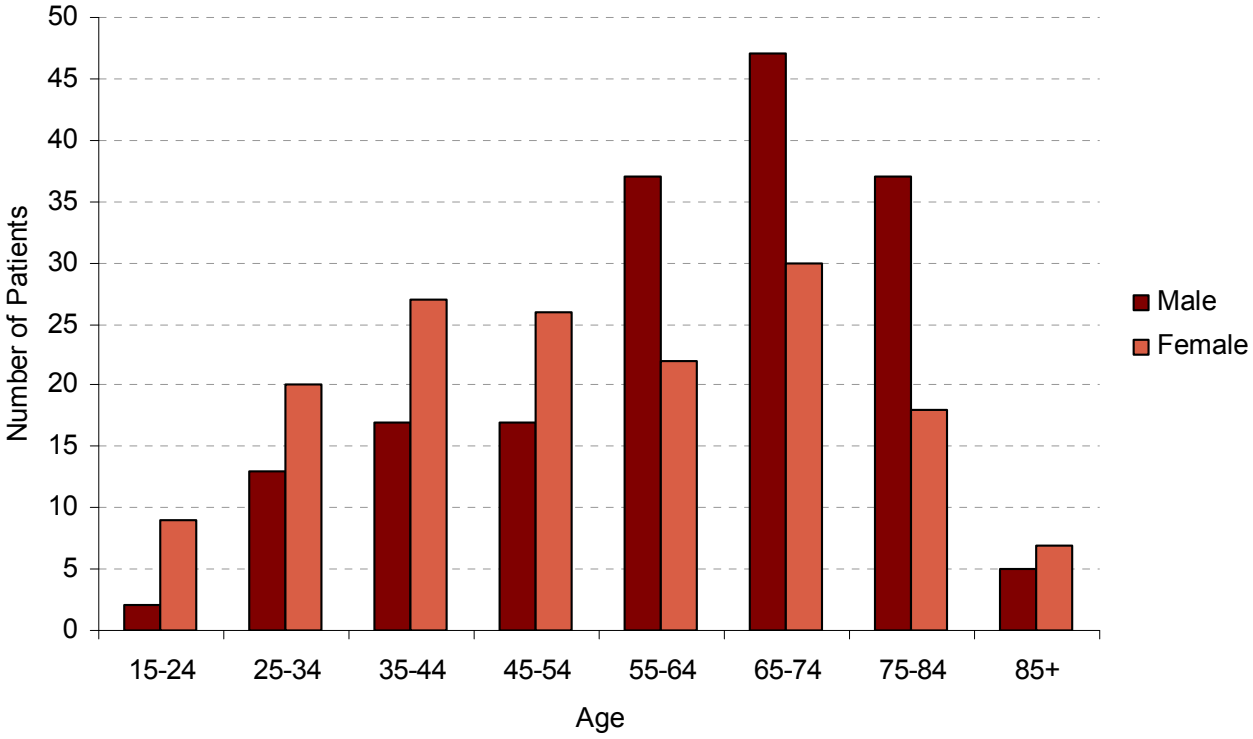
Figure 6. Age and gender profile of patients.



As can be seen in figure 7, the age of the patients in the survey followed a fairly typical distribution with most patients falling in the 55-84 year range which is what would be expected for this range of conditions.

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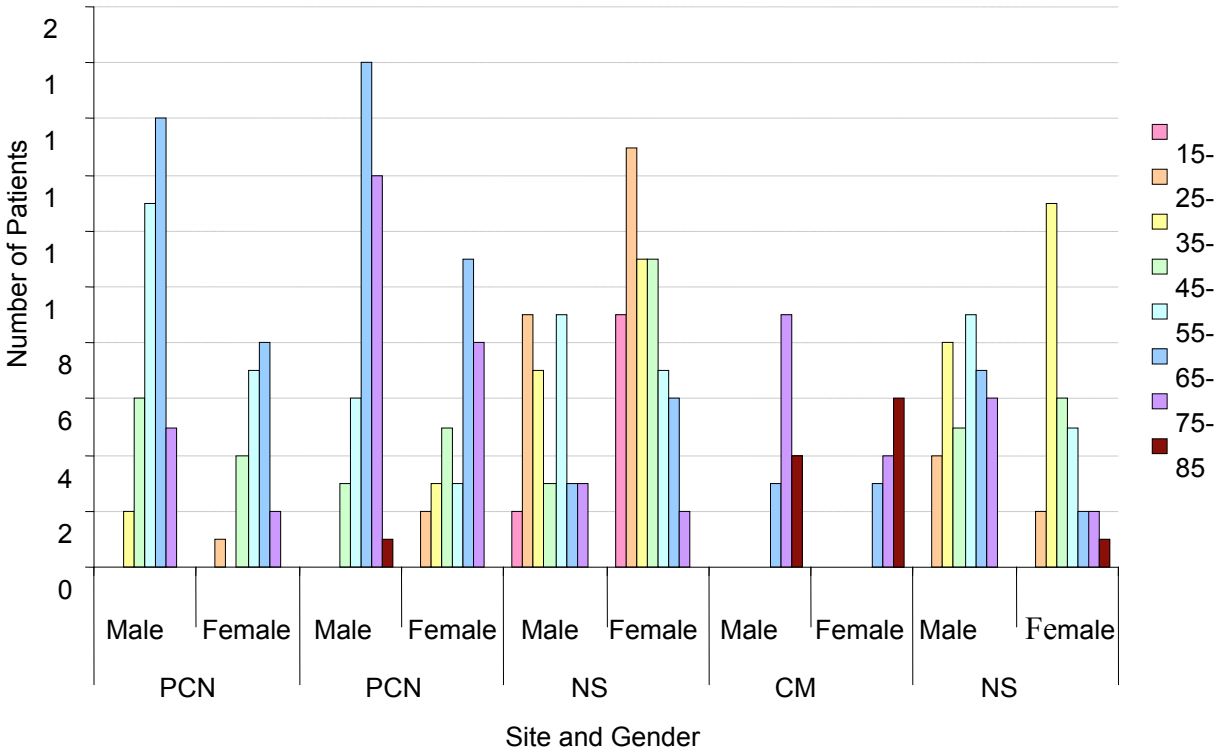
Figure 7. Age and gender profile of patients by site.



As noted above, younger patients were more likely to be in the nurse specialist model that focused on epilepsy (NS1), whilst the very old were mainly within the case management model (CM1).

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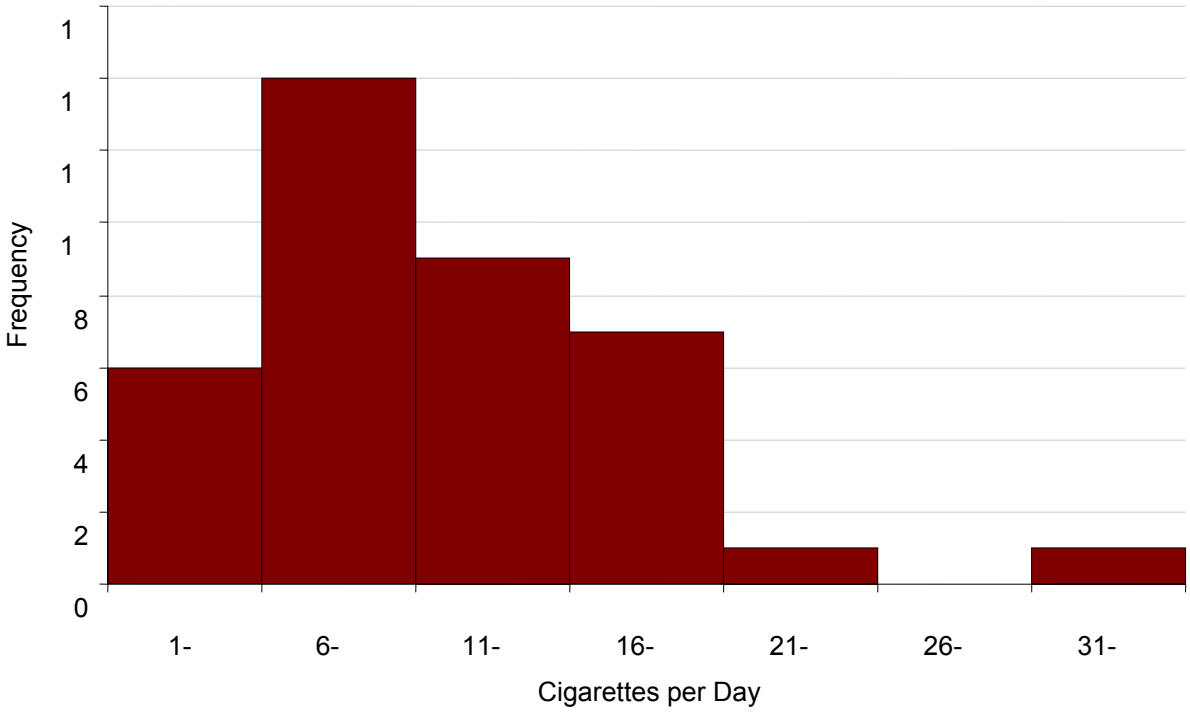
Figure 8. Distribution of cigarettes smoked per day (n=38).



As can be seen from figure 8, only 38 patients or 10.9 percent of the total number of patients (n=347) were smokers. Of these, 14 smoked 6 to 10 cigarettes a day and one person smoked 31 to 35 per day. Given this was a survey of patients with long term conditions, some of which are exacerbated by smoking, it is not surprising that the proportion of cigarette smokers was relatively low.

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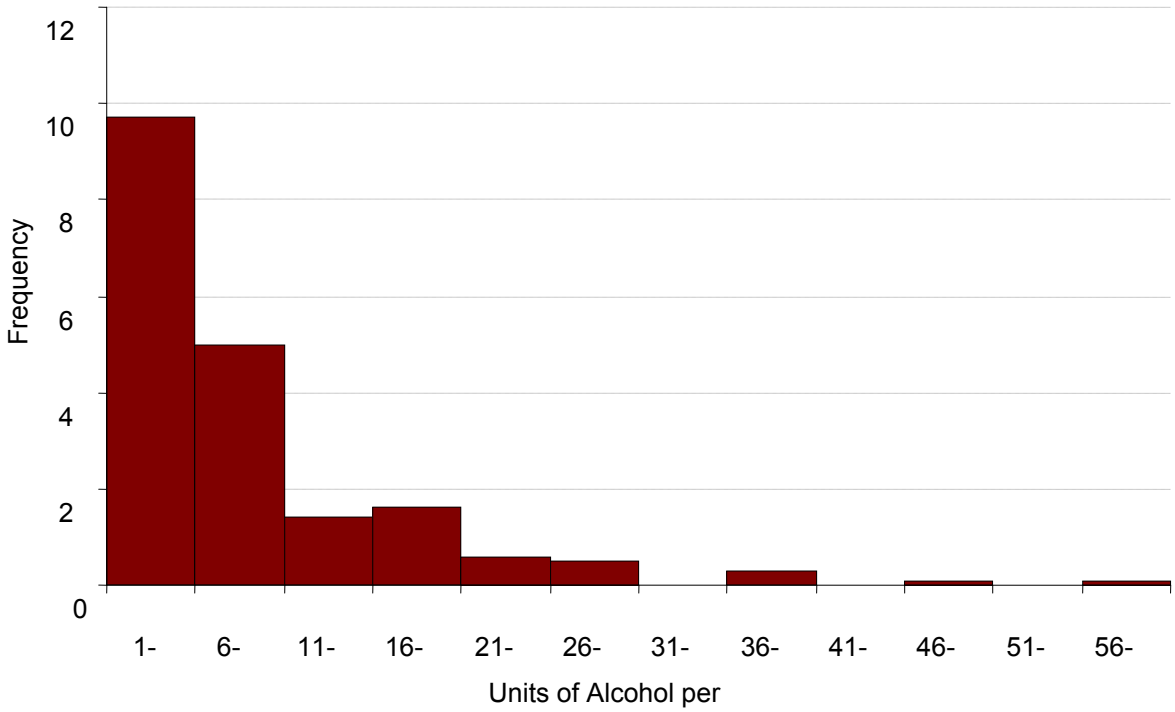
Figure 9. Distribution of alcohol consumption.



Again, it can be seen that the majority of this sample (n=347) were light users of alcohol with only a very small number reporting more than the recommended units per week for men. This is not surprising given the age and conditions that the sample was representing.

Body Mass Index

Mean body mass index (BMI) was 28. 6 (standard deviation (sd) 6.1). Appendix 22, table A3 shows BMI by site and Figure 10 shows the distribution of BMI for all patients.

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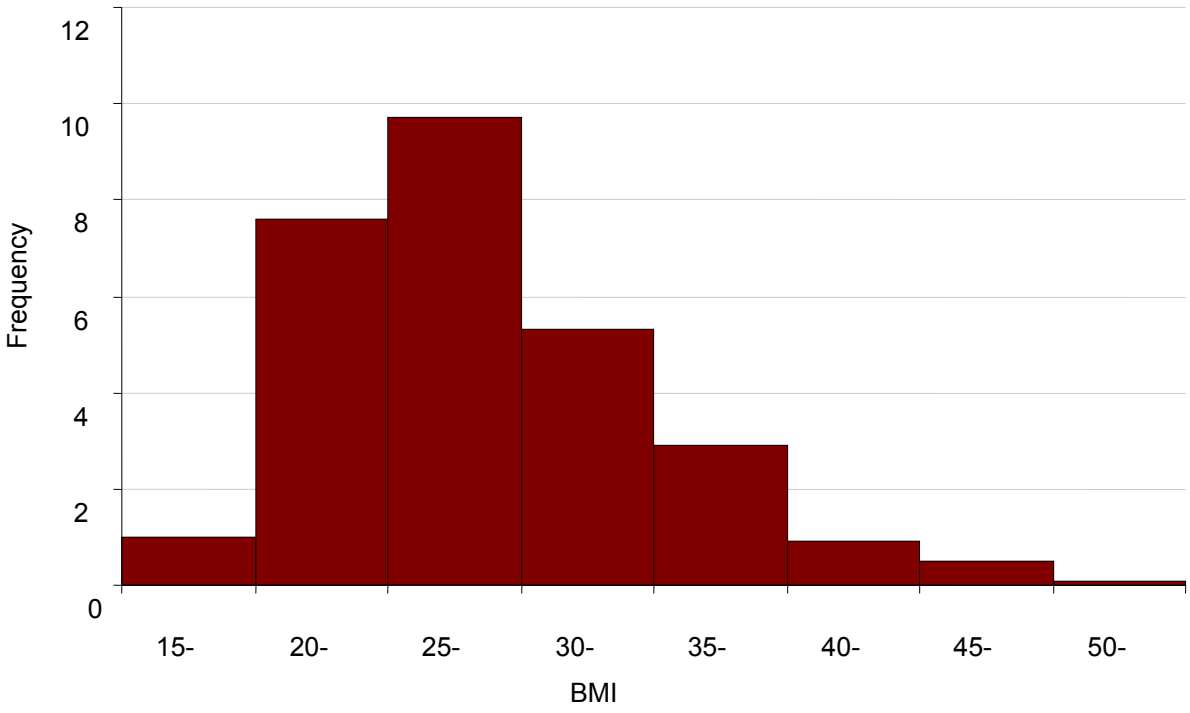
Figure 10. Distribution of Body Mass Index.



As can be seen in figure 10 , the sample overall did tend towards a BMI of 25 or more suggesting that over-weight and obesity were evident in this patient profile.

Exercise

One quarter (25.6 percent) of patients claimed to exercise daily whereas 20.7 percent claimed not to exercise at all. Figure 11 shows exercise amount overall and by individual site. Overall there is a significant ($p=0.06$) relationship between age and exercise with exercise frequency decreasing with age, however, this relationship is only observed at site CM1 ($p=0.018$), all other sites show an increase in exercise with age, though none of these relationships are significant.

Occupation

The highest proportion of people worked in a professional occupation (28.2 percent) closely followed by skilled manual professions (21.6 percent) (appendix 22, table A4). This pattern was observed at sites PCN1, NS1 and NS2, while at site PCN2 the highest proportion of people worked (or had worked) in a skilled manual (33.3 percent) occupation, and at site CM1 the highest proportion worked in either a skilled manual (20.6 percent) or non skilled manual (20.6 percent) occupation.

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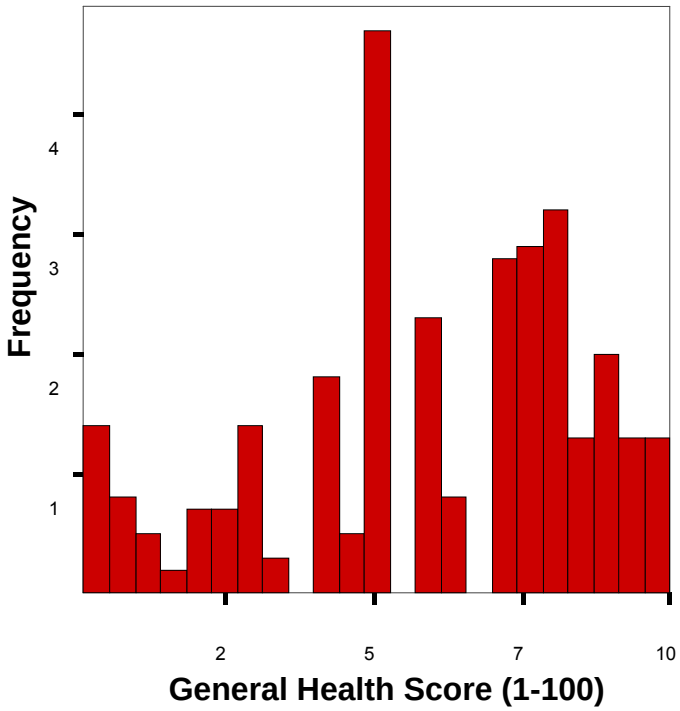
Ethnicity

Over 94 percent of the patients surveyed were of white ethnicity (appendix 22, table A5) a trend observed at all sites other than site NS2 where a little over 83 percent of patients were of white ethnicity and just over 15 percent were Asian.

General Health

When asked to assess general health on a score of 1 to 100 the mean score for all sites was 59.30 (sd 26.53) (appendix 22, table A6), while between sites the score varied from 31.82 (site CM1) to 65.92 (site NS1). Site CM1 had a significantly lower mean score than all other sites ($p<0.001$), and site PCN2 had a significantly lower mean score than site NS1 ($p=0.040$); the mean scores between all other sites were not statistically significant. Figure 12 shows the distribution of assessed health scores for the whole survey population.

Figure 12. Distribution of general health scores.



Subsequent regression analysis showed that EQ5D score ($p<0.001$) was a significant indicator for the general health score, with decreasing EQ5D score associated with a decrease in the general health score (table 19).

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Table 19. Regression analysis.

	Unstandardised Coefficients		Standardized Coefficients			95% Confidence Interval for B	
	B (Std. Error)		Beta	t	p-value	Lower Bound	Upper Bound
(Constant)	32.426	(2.997)		10.820	<0.001	26.528	38.325
EQ5D	40.919	(4.062)	0.510	10.074	<0.001	32.924	48.914

EQ5D

Mean EQ5D score in our study was 0.655 (sd 0.331) compared to 0.630 (sd 0.325) in HODaR, the difference was not statistically significant (p=0.488). Appendix 22, table A7 summarises the EQ-5D by site. Figure 13 shows the distribution of EQ5D scores for all patients. In a regression model including age, smoking status, alcohol consumption, BP, cholesterol, BMI, presence of diabetes, presence of epilepsy and site unit only age and BMI were significant predictors of EQ-5D. Table 20 shows the results of the regression model.

Figure 13. Distribution of EQ-5D scores

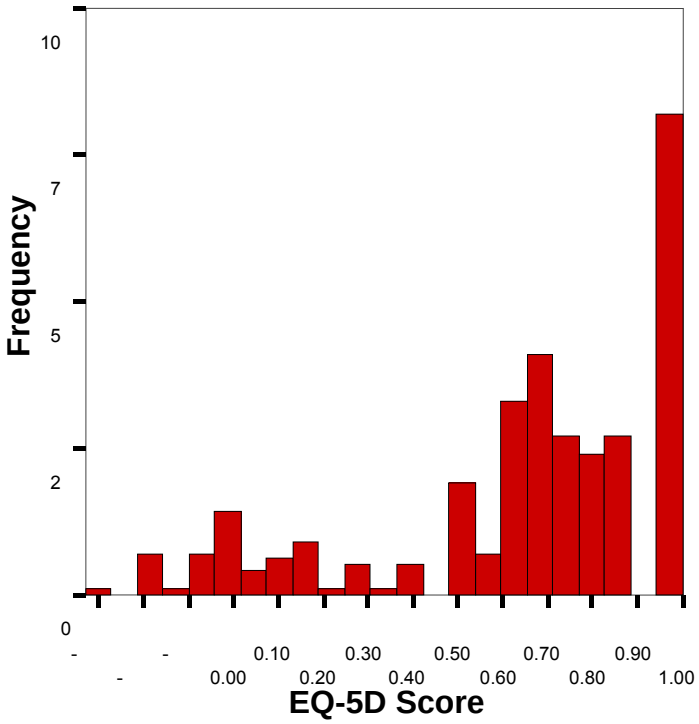

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Table 20. Results from regression model considering factors predicting EQ-5D score.

	Unstandardised Coefficients		Standardized Coefficients			95% Confidence Interval for B	
	B (Std. Error)		Beta	t	p-value	Lower Bound	Upper Bound
(Constant)	1.361	(0.105)		13.000	<.0001	1.155	1.567
Age	-0.007	(0.001)	-0.370	-6.641	<.0001	-0.009	-0.005
BMI	-0.010	(0.003)	-0.189	-3.402	0.001	-0.016	-0.004

These data indicate that younger patients and those with a lower BMI are likely to have a better quality of life. It is important to take such factors into account when interpreting the findings of each model as for example, NS1 (epilepsy) is a younger patient group a better quality of life score may be more to do with age than the nurse specialist model.

It could also be seen that people with epilepsy (p=0.001) had a significantly greater EQ-5D score in our study (mean 0.761; sd 0.23) than those in HODaR (mean 0.594; sd 0.38). Patients with diabetes (p=0.192) also had a greater EQ-5D score in our study (mean 0.659; sd 0.33) than in HODaR (mean 0.608; sd 0.32), while those with COPD (p=0.130) had a lower EQ-5D score in our study (mean 0.461; sd 0.32) than in HODaR (mean 0.662; sd 0.19) though neither difference was statistically significant. The significant difference between people with epilepsy (NS1) and HODaR may be explained by their model of management by a specialist nurse, the qualitative data would suggest that these patients experience high quality care which may impact on their health outcomes and quality of life. This would warrant further investigation.

Health related events

It was shown that on average those surveyed took 5.59 (sd 3.93) tablets and medicines per day, ranging from 3.62 (sd 2.98) to 8.90 (sd 4.47) between the different sites (appendix 22, table A8). Of those taking tablets or medicines the highest proportion of respondents never missed taking them (59.4 percent), a pattern observed across all sites, ranging from 53.5 percent to 70.6 percent (appendix 22, table A9). Furthermore 72.3 percent feel that they benefit either all of the time (36.6 percent) or most of the time (35.7 percent) compared to 2.0 percent who feel they benefit none of the time from taking their medication (appendix 22, table A10).

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Service Use

Those surveyed visited their GP, on average, 0.96 (sd 1.39) times in the six weeks prior to survey (appendix 22, table A11). There was no significant difference between sites. A practice nurse or health assistant was visited 0.86 (sd 1.42) times in the previous six weeks (appendix 22, table A12), with those from site CM1 visiting significantly more often than those from site PCN1 (p=0.024), site PCN2 (p=0.001), site NS1 (p=0.001), and site NS2 (p=0.047). There was no significant difference between sites with regard to visiting a NHS walk-in centre or contacting NHS direct, with an overall mean of 0.09 (sd 0.36) times in the previous 6 weeks (appendix 22, table A13). Of those surveyed, nurses had been to visit 0.81 (sd 2.62) times (appendix 22, table A14), and other health services had been to visit 0.28 (sd 1.00) times (appendix 22, table A15) in the previous 6 weeks and there were significant differences between site CM1 and all other sites (<0.001). This pattern was also seen with regard to being visited by social services (mean 1.07; sd 7.08) (appendix 22, table A16) with a significant difference between site CM1 and site PCN1 (p=0.010), site PCN2 (p=0.020), site NS1 (p=0.008) and site NS2 (p=0.003).

On average people missed 1.78 (sd 7.02) days of paid employment in the last six weeks (appendix 22, table A17), while spending an average of 5.13 (sd 11.07) days away from normal activities (appendix 22, table A18). There was no significant difference between the groups with respect to paid employment, though there was a significant difference between site CM1 and sites PCN1 (p<0.001), PCN2 (p=0.020), NS1 (p<0.001), and NS2 (p<0.001), and between site PCN2 and site NS1 (p=0.045) with respect to days away from normal activities. Overall people needed care or help from relatives or friends for 8.62 (sd 15.38) days in the last six weeks (appendix 22, table A19), with a significant difference between site CM1 and all other sites (p<0.001).

People stayed overnight in hospital, on average, 0.68 (sd 3.32) times (appendix 22, table A20) and for an average of 1.48 (sd 5.74) nights (appendix 22, table A21) in the last six weeks. There were significant differences between sites PCN1 and CM1 (p=0.033 and p=0.003), and between sites NS1 and CM1 (p=0.004 and p=0.027) respectively.

Compared to patients from our study those within HODaR visited the GP more (1.17; sd 1.12; p=0.050), made more visits to a practice nurse or health assistant (0.90; sd 1.58; p=0.676), and made significantly more visits to an NHS walk-in centre (0.29; sd 1.13; p=0.004), however, they were visited by nurses less (0.68; sd 2.83; p=0.918), visited by other health services the same (0.28; sd 1.33; p=0.753), and visited by social services less (0.53; sd 5.39; p=0.311) within the six weeks prior to survey. HODaR patients also took significantly more time off work (4.95; sd 11.85; p=0.001), significantly more time away from normal activities (9.18; sd 15.10; p<0.001), and needed more care from friends and relatives (9.47; sd 14.92; p=0.383) than patients from our study within

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the last six weeks. There were no data within HODaR regarding the number of times patients stayed in hospital overnight or the number of nights spent in hospital within the past six months, or the number of nights spent in hospital prior to this. The differences in service use between the HODaR and study site patients cannot easily be explained but it could be speculated when referring to the qualitative data that the study site patients are benefiting from nurse coordinated care. However, we could not comment on whether patients from the HODaR dataset had recent experience of any similar models of care as this information was not available.

Health and well-being

The SF12 health questions showed that overall patients had a mean physical health score of 42.26 (sd 13.55) (appendix 22, table A23) and a mean mental health score of 49.12 (sd 7.99) (appendix 22, table A24). The physical health score for patients within our study was greater than that seen in HODaR (42.94; sd 12.69) though the difference was not significant ($p=0.987$), the mean mental health score was higher in our study than in HODaR (43.21; sd 10.43) a difference that was statistically significant ($p<0.001$). Speculatively, when we take into account the higher quality of life scores and self-efficacy scores of the study respondents it could be argued that the nurse run models were having an impact on mental health. However, caution is advised again due to the probable response bias of our sample. Patients at site CM1 ($p<0.001$) had a significantly lower physical health score than patients at all other sites, while patients at site PCN2 had significantly lower physical health scores than patients at sites NS1 ($p<0.001$) and NS2 ($p<0.001$), and those at site PCN1 had a significantly lower physical score than those at site NS2 ($p=0.035$). Furthermore, patients at site CM1 had significantly lower mental health scores than those at site PCN1 ($p=0.010$), site PCN2 ($p=0.025$) and site NS2 ($p=0.014$).

Most people said that their health was fair to good (67.1 percent) with a small number claiming their health was poor (13.8 percent) and an even smaller number claiming their health was excellent (2.3 percent) (appendix 22, table A25). This was observed at all sites other than site CM1 where no one claimed to have health better than fair, with the majority claiming to have poor health (52.9 percent).

Just over half the people surveyed said that their health limited them from conducting moderate activity either a little (27.1 percent) or alot (26.2 percent), while just under half claimed that they were not limited at all (43.2 percent) (appendix 22, table A26). This varied by site with the majority of people at site PCN1 (40.6 percent), site NS1 (55.4 percent), and site NS2 (63.0 percent) saying that they were not limited at all, at site PCN2 (33.3 percent) saying they were limited a little, and at site CM1 (88.2 percent) claiming they were limited a lot. A similar trend was observed with regard to how health affected climbing stairs (appendix 22, table A27) with over half saying that they were limited a little (27.1 percent) or a lot (30.8 percent) and just over a third stating that they

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were not limited at all (37.2 percent). Again the majority of people at site NS1 (53.5 percent) and site NS2 (54.8 percent) were not limited at all, at site PCN1 the majority were split between not limited (35.9 percent) and limited a little (35.9 percent), while at site PCN2 (44.0 percent) and site CM1 (82.4 percent) people were limited a lot.

The majority of people (30.3 percent) did not accomplish less during work or other regular daily activities (appendix 22, table A28) due to their physical health, and were not limited at all (31.7 percent) in the kind of work or activities that they undertook (appendix 22, table A29). With respect to work and regular daily activity the majority at site NS1 (40.6 percent) and site NS2 (41.1 percent) accomplished less none of the time, at site PCN1 (26.6 percent) accomplished less none of the time and some of the time, at site PCN2 (26.7 percent) the majority accomplished less some of the time, and at site CM1 (61.8 percent) accomplished less all of the time due to their physical health. This was also seen with respect to the kind of work that could be undertaken with those at site PCN1 (31.3 percent), site NS1 (39.6 percent), and site NS2 (43.8 percent) limited none of the time, site PCN2 (24.0 percent) limited none of the time and some of the time, and site CM1 (55.9 percent) limited all of the time. Furthermore the majority accomplished less at work none of the time (44.1 percent) due to their emotional health (appendix 22, table A30) and conducted work less carefully than usual none of the time (42.9 percent) (appendix 22, table A31). This pattern was observed across each of the sites other than at site PCN2 where the majority of people accomplished less at work some of the time (30.7 percent) due to their emotional health. When asked if pain interfered with work the highest proportion said not at all (38.9 percent) (appendix 22, table A32), again, this was true for site PCN1 (29.7 percent), site NS1 (53.5 percent), and site NS2 (54.8 percent), while the majority at site PCN2 (29.3 percent) said quite a bit, and site NS2 (52.9 percent) said extremely.

Over the past four weeks most people felt calm and peaceful most of the time (40.6 percent) (appendix 22, table A33), had a lot of energy some of the time (29.7 percent) (appendix 22, table A34), and felt downhearted and depressed none of the time (30.8 percent) (appendix 22, table A35). The majority of people surveyed at site PCN1 (43.8 percent), site PCN2 (38.7 percent), site NS1 (40.6 percent), and site NS2 (49.3 percent) felt calm and peaceful most of the time, while at site CM1 (23.5 percent) felt calm and peaceful some of the time. People at site PCN2 (33.3 percent), site NS1 (34.7 percent), and site NS2 (34.2 percent) had a lot of energy some of the time, while at site PCN1 (29.7 percent) people had a lot of energy a little of the time, and at site CM1 (55.9 percent) the majority had a lot of energy none of the time. Again, these findings might be explained by increasing frailty and age among those in CM1. Most people at site PCN1 (46.9 percent) felt downhearted or depressed none of the time, at site PCN2 (29.3 percent) a little of the time and some of the time, at site NS1 (31.7 percent) a little of the time, at site CM1 (41.2 percent) some of the time, and at site NS2 (31.5 percent) none of the time and a little of the time.

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It was shown that for the most part (38.6 percent) physical health and emotional problems interfered with social activities none of the time (appendix 22, table A36). This was true for site PCN1 (50.0 percent), site NS1 (39.6 percent), and site NS2 (50.7 percent), though for site PCN2 (34.7 percent) the majority said their problems interfered with social activities some of the time, and at site CM1 (47.1 percent) most said that their problems interfered all of the time.

Self-efficacy in chronic disease self-management

On a scale of 1 to 10 (where 1 was not at all confident and 10 was totally confident) people were generally confident that they were able to keep their fatigue from interfering with things that they wanted to do (mean 6.30; sd 2.83) (appendix 22, table A37); keep physical discomfort or pain from interfering with things that they wanted to do (mean 6.47; sd 3.00) (appendix 22, table A38); keep their emotional distress from interfering with things that they wanted to do (mean 6.89; sd 2.77) (appendix 22, table A39); keep any other symptoms or health problems from interfering with things that they wanted to do (mean 6.33; sd 2.75) (appendix 22, table A40); do different task and activities needed to manage their health (mean 6.83; sd 2.76) (appendix 22, table A41); and do the things other than just taking medication to reduce how much illness affects everyday life (mean 6.24; sd 2.97) (appendix 22, table A42).

Those at site CM1 ($p<0.001$) were significantly less confident than those at all her sites in their ability to do any of the above factors. Furthermore, those at site PCN2 ($p=0.006$) were significantly less confident than those at site NS2 in their ability to keep their fatigue from interfering with things that they wanted to do. Those at site PCN1 were significantly less confident than those at site NS2 ($p=0.043$) and those at site PCN2 were significantly less confident than those at site NS1 ($p=0.001$), and site NS2 ($p<0.001$) at being able to keep their physical discomfort or pain from interfering with things that they wanted to do. Those at site PCN2 ($p=0.018$) and site NS1 ($p=0.036$) were significantly less confident than those at site NS2 in their ability to keep their emotional distress from interfering with things that they wanted to do, while those at site PCN2 ($p=0.025$) were also significantly less confident than those at site NS2 in their ability to keep other symptoms or health problems from interfering with things that they wanted to do. People at site PCN2 ($p=0.003$) were also significantly less confident than those at site NS2 in their ability to do different tasks to manage their health, while those at site PCN2 were significantly less confident than those at site PCN1 ($p=0.027$) and those at site NS2 ($p=0.013$) in their ability to do things other than just take medication to reduce how much their illness affects everyday life.

On average, across all six self-efficacy items, people were generally confident that they could undertake certain activities (mean 6.50; sd 2.55) (appendix 22, table A43), a pattern observed across all sites except site CM1 where confidence was significantly lower ($p<0.001$) than at all other

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sites, there was no significant difference observed in confidence between any other sites except between sites PCN2 and NS2 (p=0.002).

6.2.2 Summary

Overall our sample of adults with long-term conditions from across five different sites representing three models of nurse coordinated care, compared favourably with a matched group of patients from the HODaR dataset. This would suggest that our patients are not unusual in their demographic profile. Compared to patients within our study those within HODaR visited the GP more and made more visits to an NHS walk-in centre, within the six weeks prior to survey. HODaR patients also took more time off work and more time away from normal activities than patients within our study within the last six weeks. Patients in our study stayed overnight in hospital, on average, 0.7 times and for an average of 1.5 nights in the last six weeks. Whilst we have attempted to report on some between case differences, these should be treated with caution due to the very low response rate to our survey. Some of the differences that were noted could be attributable to the type of patient within the model. For example, in CM1 we observed less energy and lower levels of confidence and self-efficacy, but patients within the case-management model were typically older and frailer with more than one long-term condition. Equally, patients from NS1 scored more highly for quality of life and health and well-being but these patients were also younger than those from the other case studies. Whilst in combination with the qualitative evidence there are some indications that nurses are contributing to the quality of life, health service use and self-efficacy of these patients, it cannot be definitively stated that any specific model of chronic disease management is more likely to improve the patient experience than another.

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7 Economic Analysis

7.1 Introduction

The work reported in this section was undertaken by the Health Research Group in the Economics Department at the University of Surrey. The Group was asked to join the PEARLE research team during the last year of the study because the designated health economist had left the project to take up a new post in another university. By this stage the recruitment and main data collection phases were over, and this significantly limited the scope of the economic analysis that could be undertaken. In particular, the original objective of the study – to define the key characteristics of cost-effective chronic disease management (CDM) – could not be achieved because outcome data were not available. The patient level data that had been collected were cross-sectional and descriptive of the patient populations served by nurses in each of the models, and did not permit the investigation of differential outcomes. Moreover, the comparative case study design comparing nurses engaged in CDM in a variety of settings does not lend itself to cost-effectiveness analysis. Meaningful comparisons between nurse models are impeded because the patient groups served by the nurses in the different models have different conditions, levels of dependency and needs.

Hence, within the constraints of the time and resources remaining in the study, a simple costing exercise was undertaken to ascertain the average (per patient) cost of the nurse contribution to CDM in each of the models. In addition, further analyses of the data collected by the HODaR survey of patients on their retrospective utilisation of health and social care were requested. Although the sampling, low response and reliability of some of the questionnaire items were issues of concern, estimates of the costs of self-reported service utilisation were made, subject to the limitations of the data.

Aims

1. To estimate and compare the average (per patient) cost of the nurse contribution to CDM in each of the models, and to evaluate this in the context of nurses' overall activities and the patient groups they served.

2. To compare patients' self-reported health and social care utilisation amongst the different service provision models.

3. To estimate and compare the costs of self-reported health and social care utilisation amongst the CDM models.

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7.2 Data collection and methods

1. Nurse activity data and costs of service delivery

Data on nurse activity were gathered via self-report audits. A proforma was prepared, piloted on two nurses independent to the study (a practice nurse and respiratory nurse specialist) and refined in light of their feedback. Each nurse member from each adult CDM model was asked to record the start and end time of various activities (direct patient contact by face to face or telephone, correspondence or meetings about patients, management functions, teaching/ mentoring/research, other) on one page per day, over a period of two weeks. Within the proforma, the nurses were also asked to state where the activity occurred (e.g. GP surgery, patient's home, hospital outpatient clinic), equipment used (if any), details of any travel involved, and interactions with other team members. Such methods have been used previously for logging activity and estimating caseloads and costs (Zeliff Massie, 1996).

Data collected from the activity reports of nurses were supplemented with information obtained through interviews with them, particularly regarding the number of patients registered in their lists. The total staff costs per team were estimated using validated national unit costs of health and social care staff (Curtis, 2008). The annual staff costs, including employers' on-costs and administration and site overheads, and using the midpoints of grades, were applied according to the staff mix for each team in each site. The average cost per patient was calculated by dividing the total staff costs for each team by the reported patient list size of each nurse model.

2. Patient health and social service utilisation

HODaR survey data included retrospective self-reporting of service use by respondents, with six week recall for community health and social care services, time of work and usual activities, informal care, and six month recall for hospital stays. Differences between sites in mean utilisation of each service were explored.

Associations between different types of services across all sites were investigated using Pearson's bi-variate correlations. Generalised linear regression modelling (forward and backward conditional method conducted by HODaR) was used to explore site and patient characteristics (gender, age, BMI, smoking behaviour, physical activity, self-rated health, number of prescribed medications, blood pressure, average score of six self efficacy items, health-related quality of life from SF-12 PCS and MCS, and EQ-5D health utility index) as predictors of eight items of service use (GP contact, practice nurse or HCA (health care assistant) visits, walk-in/NHS direct contact, nurse home visits, other health staff home visits, social services home visits, in hospital stays, and number of nights spent in hospital). Statistical significance was set at $p<.05$. Other studies have investigated differences between alternative models of care by this method (Kaambura et al, 2008).

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3. Costs of patient health and social service utilisation

Mean costs of service utilisation were calculated for community service use by patients in each of the nurse models by applying nationally validated tariffs for staff time or consultations (Curtis, 2008) to the mean utilisation figures. Costs for social services staff visits, informal caring and hospital stays were not estimated because ambiguities in the wording of the questions would render the estimates inaccurate. Respondents were asked to report on the use of social workers (relatively highly paid) and home help (low paid) in the same question, and the numbers reported could not be separated. The question on informal caring (how many days have friends or relatives needed to care for you or help you?) was insufficiently precise to enable costs to be calculated with any degree of precision. The reasons for hospitalisations were not stated, and since the level of care received can affect costs by as much as £1000 per night (National Schedule of Reference Costs, 2007/8), meaningful costs could not be calculated. Large numbers of missing observations meant that the productivity costs of days off work or normal activities could not be estimated.

7.3 Results

1. Nurse activity reporting and costs of service delivery per patient

Many nurses were not able to complete the proforma for reporting their activities due to pressure of work and time constraints. Hence, the data received were sparse and variable. Only the lone practice and specialist nurses both completed the full two weeks of data collection. In the hospital site consisting of diabetes nurses, only one member of the team completed the proforma. No data were provided by community matrons or by the primary care nurse team. A summary of the data received, by model, is shown in Table 21. Data from interviews were used to supplement the activity proforma returns where needed and available. Some of the nurses had part-time contracts. Nurses reported spending varying proportions of their time on direct patient contact (from 100 percent by nurse specialist in primary care to 21 percent by hospital diabetes nurse specialist). Time not spent on direct patient contact was designated for administration, management, teaching, mentoring and research related to CDM. The primary care practice nurse team was engaged for 50 percent of their time on activities that were not CDM, such as running women's health clinics.

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Table 21. Summary of the activity audit proformas of nurses and interview data in adult CDM models

Model	Site / working arrangements	Days of proforma completed	Patient loads for CDM (from interview data)	% of time on CDM patient contact*	Other time allocation	Comments (from proformas and interview data)
Primary Care	Diabetes specialist nurse (DSN) - 0.2 FTE	2 days (i.e. 1 day per week x 2 weeks)	N=312 (Type 2 diabetes)	100%	-	Type 1 diabetes patients treated in hospital. DSN runs clinics including 6 monthly reviews of patients, and liaises with GP as necessary (QOF related).
	Practice nurse team comprising: Nurse practitioner - 1.0 FTE 2 practice nurses - 1.4 FTE HCA - 0.5 FTE	Not available	Practice population is 8500. Asthma: ~300 COPD: ~180 Diabetes types 1&2: ~50 + 200 CHD: ~300 HT: ~1000	Not available	Not available	The practice runs clinics for 5 different chronic diseases on the basis of registers of patients and recall of patients. Practice nurse estimated spending 50% of their time on CDM (QOF related). Patients with type 1 diabetes also attended hospital clinics.
Hospital Based Nurse	Epilepsy nurse specialist -	10 days	>1000 on list, and reported 25 per week (5 new,	70%	12% administration /management e.g. seeing drug reps,	Runs clinics in hospital and liaises with the consultant as needed. Also does ward assessments/reviews and home

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Specialists	1.0 FTE		16 follow up, 4 varied enquiries) = 1200 consultations pa. Activity audit showed 59 face to face, 8 phone consultations = 6.7 per day, 1500 pa		staff appraisal 10% teaching, mentoring students and other health professionals 8% continuing professional development	visits.
	Specialist diabetes clinic and outreach service, comprising: Nurse consultant - 1.0 FTE Diabetes specialist nurses - 2.8 FTE HCA - 1.0 FTE	4 days (by nurse consultant)	Approximately 8000 patients on the lists of two hospitals but there may be some double counting	21% 62%	administration /management e.g. budgets, meetings and writing minutes, interviewing staff 15% teaching, mentoring, research, including teaching at university and writing research proposals	Main role of nurse consultant is strategic development, and developing and running patient education programmes. DSN run hospital-based clinics (independently and with consultant), GP based clinics, and patient education programmes (takes ~2 days per week for one nurse). This team tends to see the complex patients, whilst practice nurses in GP surgeries manage the rest.

*Includes face to face contact, telephone calls, writing patient notes and discussing patient issues with other health professionals. [CDM]Chronic disease management, [DSN]Diabetes Specialist Nurse, [FTE]Full-time equivalent, [GP]General Practitioner, [QOF]Quality and Outcomes Framework, [HCA]Health care assistant, [COPD]Chronic obstructive pulmonary disease, [CHD]Coronary heart disease, [HT]Hypertension, [pa]per annum, [reps]representative

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Total costs per CDM model, and average cost per patient are shown in Table 22. The calculations are based on national rates for the annual costs (2007/8) of practice and diabetes nurse specialists of £44,248 pa, nurse consultant, nurse practitioner and community matron of £61,880 pa; HCA of £22,356 pa (Curtis, 2008). The unit costs used in the calculations reflect the midpoints of the salary bands, and include employer oncosts and overheads in terms of administration and site costs.

The patient caseloads are the important factor in determining the average (per patient) costs for each of the CDM models (higher caseloads lower the average cost). Uncertainties surrounding the caseload data are reflected in the ranges of average costs shown in three of the sites (Table 22). The low caseloads of the community matron mean that the average costs per patient are higher (£1237.60) than those of all of the other models (all <£50 except the epilepsy nurse specialist for whom the average cost is estimated to be between £60 and £85). This reflects the explicit role of community matrons to provide intensive input and coordinate care for people with complex conditions with a view to averting costly hospitalisations. The patients recruited to this study who were treated by community matrons were markedly older and less healthy than those under the care of the nurses in the other CDM models (Table 23). They reported lower self-efficacy (for self management) than patients in the other nurse models (mean score of 3.5 vs. 6.2 – 7.4).

Table 22. Total and per patient cost by model

Model	Site / working arrangements	Patient CDM loads (from interview and where available, audit data)	Total cost per annum 2007-8*	Nurse cost per listed patient
Primary Care	Diabetes specialist nurse (DSN) 0.2 FTE	N=312 (Type 2 diabetes)	£11,062	£35.50
	Practice nurse team comprising: Nurse practitioner - 1.0 FTE 2 practice nurses - 1.4 FTE HCA - 0.5 FTE	Practice population is 8500. Asthma:~300 COPD: ~180 Diabetes types 1&2: ~50 + 200 CHD: ~300 HT: ~1000 Total: 2030,	£135,005 = £67,500 based on estimate by practice nurse estimated that 50% of their time spent on CDM	£33.25 (£45.00 with 1500 patients)

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		but some patients will have >1 disease		
Hospital Based Nurse Specialists	Epilepsy nurse specialist - 1.0 FTE	>1000 on list, and reported 25 per week (5 new, 16 follow up, 4 varied enquiries) = 1200 consultations pa. Activity audit showed 59 face to face, 8 phone consultations = 6.7 per day, 1500 pa	£61,880	£61.80 if assume total patient load is 1000 (£82.51 with 750 patients)
	Specialist diabetes clinic and outreach service, comprising: Nurse consultant - 1.0 FTE Diabetes specialist nurses - 2.8 FTE HCA - 1.0 FTE	Approximately 8000 patients on the lists of two hospitals but there may be some double counting	£208,130	£26.02 with 8000 patients (£34.69 with 6,000 patients)
Community matron	Nurse-led case management of people with complex conditions	Approximately 50	£61,880	£1237.60

*Based on data in Curtis, 2008, and including overheads. [CDM]Chronic disease management, [DSN]Diabetes Specialist Nurse, [FTE]Full-time equivalent, [HCA]Health care assistant, [COPD]Chronic obstructive pulmonary disease, [CHD]Coronary heart disease, [HT]Hypertension, [pa]per annum

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Table23. Comparison of patient characteristics across sites (Data from HODaR analysis)

Model	Site	Total N	Age in years Mean *SD*, range	Gender				Number of prescribed medications			Self assessed health 0-100 (best)		EQ-5D 0-1 (best)		SF-12: PCS 0-100 (best)		SF-12: MCS 0-100 (best)	
				n	% male (n)	% female (n)	n	mean *SD*	median IQ range	n	mean *SD*	n	mean *SD*	n	mean *SD*	n	mean *SD*	n	mean *SD*
Primary Care	Diabetes specialist nurse	64 62.	7 *10.4*, 34-84	64 65.	6 (42)	34.4 (22)	62 5.	44 *3.68*	5 2.75-8	60 58.	95 *28.30*	59 .	60 *.37*	54 42.	76 *10.96*	54 50.	97 *8.84*	
	Practice nurses	75 66.	8 *12.7*, 26-86	74 56.	8 (42)	43.2 (32)	74 6.	65 *3.95*	6 4-9	67 57.	42 *25.62*	74 .	62 *.32*	59 39.	17 *11.40*	59 49.	69 *7.75*	
Hospital-based Nurse Specialists	Epilepsy nurse specialist	101 45.	0 *16.5*, 17-77	97 37.	1 (36)	62.9 (61)	93 3.	62 *2.98*	3 1-5	84 65.	92 *24.48*	93 .	78 *.25*	85 45.	73 *14.05*	85 48.	45 *7.35*	
	Diabetes team	73 53.	9 *15.9*, 25-85	70 55.	7 (39)	44.3 (31)	73 5.	78 *3.68*	5 3-9	71 64.	00 *22.07*	68 .	76 *.27*	66 47.	16 *11.53*	66 49.	66 *6.77*	
Community matron	Community matron	34 79.	7 *7.0*, 68-92	29 55.	2 (16)	44.8 (13)	30 8.	90 *4.47*	8 5-12	27 31.	82 *25.23*	32 .	25 *.34*	23 26.	46 *2.17*	23 44.	86 *10.50*	

[N]Total number of respondents, [SD]Standard deviation, [n]number of respondents, [IQ]Inter-Quartile

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2. Patient health and social service utilisation

The HODaR patient survey provides comparative self-report data on service utilisation (Table 24). There was considerable variability in the number of responses across items. Patients treated by the hospital diabetes team and community matrons report higher rates of hospitalisations than the patients of nurses in the other models. Reflecting the more complex nature of their conditions, respondents from the community matron site also report higher rates of: days off normal activity/work (although no respondents in this group were in employment); informal/family or friends caring; nurse visits; other health and social service staff contacts. Their use of GP services, however, was largely equivalent to that of patients in the other nursing models (Table 24).

Pearson's correlations between service-use items for all patients providing data in the study are shown in Table 25. Use of different health professionals and services are positively associated. For example, greater use of other NHS services is associated with the reporting of more nurse and social service visits. A main objective of CDM is to avoid costly hospitalisations, and it is recognised that extra community resources may be required to achieve this. However, there is no evidence from data available in this study that nursing or other health professional or social service input substitutes for hospital stays, or for use of GP services. Although statistically significant, the correlation coefficients for many of the paired comparisons are relatively low. The strongest association observed is between visits to GP and number of nights spent in hospital. The number of prescription items (a proxy for severity of condition) correlates positively and significantly with most major service utilisation items.

Generalised linear regression modelling was used to explore associations between eight service use items and patient characteristics. Study site was also entered into the models as a further independent variable to capture the type of CDM. The results are shown in Table 26. The SF-12 PCS is negatively associated with GP contacts, nurse home visits and hospitalisations (worse self-reported physical health is associated with higher service use). Lower self- efficacy is associated with greater use of NHS walk-in/NHS direct. Worse self-rated health is associated with greater nurse contacts. Lower EQ-5D utility scores (health-related quality of life) predict greater social service and other health professional utilisation, but less nurse visits. Older age and interestingly, lower BMI and not smoking are associated with more visits from other health professionals. Site/type of nurse CDM was not significant in any of the regression analyses. The values of most of the coefficients are relatively low, and the regression models explain small proportions of the variation in the dependent variables, so the findings should be interpreted with caution.

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Table 24. Comparison of patient reported health and social service use across sites (Data from HODaR analysis)

Service use: number in last 6 weeks	Primary Care						Hospital-based Nurse Specialists						Community matron (Patient sample n=34)		
	Diabetes specialist nurse (Patient sample n=64)			Practice nurses (Patient sample n=75)			Epilepsy nurse specialist (Patient sample n=101)			Diabetes team (Patient sample n=73)					
	n	Mean	*SD*	n	mean	*SD*	n	mean	*SD*	n	mean	*SD*	n	mean	*SD*
Number of times seen GP	62	.92	*1.0*	68	.88	*1.88*	91	1.12	*1.53*	72	.89	*.97*	31	.90	*1.27*
Visits to Practice nurse/HCA	59	.97	*.93*	69	.62	*1.13*	90	.71	*1.02*	69	.83	*1.94*	30	1.70	*2.09*
Visits to NHS walk-in/contacts NHS direct	52	.02	*.14*	60	.05	*.29*	82	.15	*.50*	67	.10	*.35*	26	.12	*.33*
Home visits from nurses	52	.29	*1.68*	62	.63	*2.52*	84	.26	*1.44*	69	.33	*1.63*	32	4.44	*4.68*
***Visits from other health professionals**	51	.18	*.56*	63	.14	*.44*	84	.24	*1.26*	67	.07	*.32*	27	1.34	*1.82*

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#Visits from social services	51	0	*0*	61	.74	*5.38*	82	.82	*4.85*	67	.02	*.12*	28	6.96	*18.95*
Days off paid employment	43	1.19	*6.49*	53	3.17	*10.48*	71	1.96	*5.63*	57	1.23	*5.89*	17	0	*0*
Days off normal activities	50	3.58	*7.7*	62	6.81	*12.95*	79	3.30	*7.34*	65	3.52	*9.35*	21	15.76	*19.77*
Number of days relatives or friends cared / helped	52	6.23	*13.20*	66	8.05	*14.75*	84	5.57	*11.88*	63	4.73	*12.32*	30	31.13	*16.91*
Number of times patients stayed overnight in hospital <u>in last 6 months</u> due to chronic disease	50	.30	*1.52*	61	.53	*1.99*	82	.26	*.93*	67	1.15	*5.66*	28	1.82	*4.55*
Number of nights spent in hospital <u>in last 6 months</u> due to chronic disease	51	.216	*.76*	62	1.81	*7.11*	83	.76	*2.78*	68	2.59	*8.57*	27	2.52	*5.27*

[GP]General Practitioner, [HCA]Health care assistant, [NHS]National Health Service, [n]number of respondents, [SD]Standard deviation

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*For example: physiotherapist, occupational therapist, chiropodist. #For example: social worker or home help.

Table 25. Correlation between different types of service use, for patients in all CDM models (Data from HODaR analysis)

		Visits to PN	Visits to NHS walk-in centre/ NHS Direct	Visited by nurses	Visited by other NHS services	Visited by Social Services	Times stayed overnight in hospital	No. of nights stayed in hospital	No. of prescriptions
Visits to GP	Correlation	.143*	.144*	.122*	.091	.012	.199**	.451**	.185**
	Sig. (2-tailed)	.012	.015	.036	124	.846	.001	.000	.001
	N	311	286	294	287	286	284	285	315
Visits to PN	Correlation		-.021	.061	.107	.026	.247**	.104	.143*
	Sig. (2-tailed)		.724	.297	.071	.658	.000	.081	.013
	N		285	293	287	285	283	283	305
Visits to NHS walk-in centre/NHS Direct	Correlation			.052	.109	-.013	.119*	.149*	.040
	Sig. (2-tailed)			.379	.067	.832	.047	.013	.507
	N			285	283	282	276	277	279
Visited by nurses	Correlation				.276**	.070	.173**	.157**	.346**
	Sig. (2-				.000	.237	.003	.008	.000

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	tailed) N				289 286		285	286	288
Visited by other NHS services	Correlation Sig. (2-tailed) N					.408** .000 288	.061 .309 279	.160** .007 282	.238** .000 283
Visited by SS	Correlation Sig. (2-tailed) N						.121* .045 277	.166** .005 280	.034 .570 279
Times stayed overnight in hospital	Correlation Sig. (2-tailed) N							.601** .000 284	.233** .000 280
No. of nights stayed in hospital	Correlation Sig. (2-tailed) N								.182** .002 282

[PN]Practice Nurse, [GP]General Practitioner, [NHS]National Health Service, [SS]Social Services, [No.]Number, *Correlation is significant at .05 level (2-tailed), **Correlation is significant at .01 level (2-tailed)

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Table 26. Results of generalised linear regression modelling, based on patients in all CDM models (Data from HODaR analysis)

Dependent variable Number of times:	n	Statistically significant independent variables*	B	Std Error	t	*p*	95% confidence intervals for B	r^2
Seen GP in last 6 weeks	271	SF-12 PCS	-.030	.006	-4.712	<.001	-.043 to -.017	.083
		Physical activity	-.109	.036	-3.003	.003	-.180 to -.037	
Visited practice nurse/health care assistant in last 6 weeks	285	Self-rated health	-.007	.003	-2.163	.031	-.013 to -.001	.016
Visited NHS walk in/NHS Direct in last 6 weeks	284	Mean self efficacy score	-.021	.008	-2.476	.014	-.038 to -.043	.021
Nurses have visited in last 6 weeks	230	SF-12 PCS	-.062	.023	-2.729	.007	-.107 to -.017	.239
		Self-rated health	-.016	.008	-2.147	.033	-.031 to -.013	
		EQ-5D utility score	1.685	.794	2.122	.035	-.107 to -.017	
		Number prescribed meds	.190	.008	-2.147	.033	-.031 to -.013	
Visited by other NHS staff in last 6 weeks	228	EQ-5D utility score	-.741	.219	-3.380	.001	-1.173 to -.309	.180

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		Age	.013	.002	3.195	.002	.049 to .021	
		Smoker	-.666	.216	-3.079	.002	-1.092 to -.240	
		BMI -.026		.011	-2.492	.013	-.047 to -.006	
Visited by social services in last 6 weeks	273	EQ-5D utility score	-5.767	1.347	-4.280	<.001	-8.419 to -3.114	.063
In hospital (overnight stays) in last 6 months	253	SF-12 PCS	-.049	.010	-4.856	<.001	-.069 to -.029	.086
Number of nights in hospital in last 6 months	254	SF-12 PCS	-.117	.025	-4.594	<.001	-.167 to -.067	.077

[NHS]National Health Service, [n]number, [meds]medications, [BMI]Body Mass Index, *constant not shown

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3. Costs of patient health and social service utilisation

The costs of community service use by respondents in the different CDM models over the six-week recall period are shown in Table 27. As expected, the mean (per patient) costs of community service use are proportional to utilisation rates (Table 26). Patients cared for by the community matrons incur community health and social care costs that are three or four times higher than those of the patients in the other models (Table 27). This difference is driven largely by a greater number of home visits from nurses and other health care professionals received by the patients in the community matron sample, and may reflect the more complex needs of this patient population (Table 23). Moreover, the explicit role of community matrons is to coordinate care for this high need group of patients in order to avert costly hospitalisations. It should be noted that, in many instances, the standard deviations for utilisation of services are large so the costs (which are based on mean values) should be interpreted with caution.

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Table 27. Mean costs (over 6 weeks) of community service utilisation by nursing model

Mean costs were estimated by multiplying the mean service utilisation (Table 23) by unit costs (Curtis, 2008).

Service	Unit costs	Primary care		Hospital-based nurse specialist		Community matron
		Diabetes specialist nurse	Practice nurse	Epilepsy	Diabetes team	
Number of times seen GP	£47 per consultation[2]	£43.24	£41.36	£52.64	£41.83	£42.30
Visits to Practice Nurse/HCA	£8.70 per visit[3]	£8.44	£5.39	£6.18	£7.22	£14.79
Home visits from nurse	£26 per visit	£7.54	£16.38	£6.76	£8.58	£115.44
Visits from other health professionals[1]	£43 per visit[4]	£7.74	£6.02	£10.32	£3.01	£57.62
Visits to walk-in/contact NHS Direct	£27 per visit/contact[5]	£0.54	£1.35	£4.05	£2.70	£3.24
All services mean cost		**£67.50**	**£70.50**	**£79.95**	**£63.34**	**£233.39**

Notes:

1. For example, physiotherapist, occupational therapist, chiropodist

2. Mean of £36 (cost per consultation in GP surgery) and £58 (cost per GP home visit).

3. Mean of £11 (cost per consultation of Practice Nurse) and £6.40 (cost per consultation of HCA).

4. Mean of £47 (cost of home visit of physiotherapist, speech and language therapist), £46 (cost of home visit of occupational therapist) and £20 (cost of home visit of chiropodist).

5. Mean of cost of NHS Direct call and NHS walk-in visit. From written Parliamentary answer from Mr Bradshaw MP to Dr Fox: Average cost of call to NHS Direct 2007/8 = £25.53 http:www.publications.parliament.uk/pa/cm200809/cmhansard/cm090203/text/90203w0029.htm

6. Mean cost of NHS walk-in visit £23.54 in 2002, accounting for inflation becomes £29 in 2008 (Salisbury, 2002a).

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7.4 Discussion

This high level analysis indicates that nurse costs per patient are at least ten times higher for community matrons conducting CDM than for nurses who conduct such functions in other service delivery models and settings.

Patients cared for by community matrons report similar rates of GP contact as the patients in the other CDM models, but significantly higher use (and hence costs) of community matron, other health professional and social services, and informal care. Their hospital stays are also higher than patients treated in the other CDM models, except for people with diabetes attending the specialist hospital outpatient team for whom self-reported rates of hospital stay are broadly similar. Patients of community matrons have lower self efficacy and more complex health needs than patients in the other CDM models, and the pattern of service utilisation observed in this study is consistent with the focus of the community matron role to provide intensive input and coordinated packages of care that enable this vulnerable group to remain supported in the community setting. However, it is not possible to say how far this higher level of community service provision averts hospitalisations. Similarly, it is not known whether the extra nursing and other health professional input received from community matrons substitutes for GP contact.

Across all patients in the study, small but significant positive associations were observed between all elements of service use. Heavier use of nurses and GPs was associated with the reporting of more nights in hospital and taking more medications, suggesting that disease severity is a driver of service use. No evidence was found to suggest that community services substitute for hospital use. Exploratory regression analyses indicate that worse self-reported health or health-related quality of life predicted greater service use (GP, nurse, other health professionals, social services, in hospital stays), but nursing model was not a significant predictor of utilisation in any of the investigations.

Limitations of the economic analysis

There are many limitations to the economic analysis. The mean (per patient) costs of CDM in the different models are imprecise because of uncertainties in the size of the nurse caseloads. In most cases, nurses reported global list estimates, rather than counting active cases, and it is likely that there are considerable margins of error in the estimates. The relatively small differences in estimated average costs per patient among the primary care and hospital CDM models may not be secure. However, the magnitude of the difference between the average per patient cost associated with community matrons and the other models is credible given that the ethos of the community matron role is to provide high intensity support to relatively small numbers of patients with complex needs. The average costs per patient are based on validated national tariffs, and include employer on-costs, and site and administrative overheads, but some other treatment related costs, such as travel, are not included. Most

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nurses asked to provide activity data were unable to do so due to pressure of work, and this impeded the conduct of a more detailed costing analysis. Future analyses of the activity of nurses should be by observation, rather than self-report, to improve validity and remove the burden of recording from the participant.

The patient health and social care utilisation and costs are based on responses to the HODaR survey instrument. As previously acknowledged, there were limitations on the data due to possible problems with the sampling frame and non-response bias. Approximately 300 questionnaires were mailed to patients in each of the primary care and hospital nurse CDM models, but patients contacted may not have been representative of the whole patient population due to variations in case-load size, and respondents (between 20 percent and 25 percent of those receiving questionnaires) were a self-selected sample. Phrasing of the questions on service utilisation restricted the usefulness of the data, particularly for the calculation of the costs, and many respondents failed to provide data for some of the items, which reduced the size of the sample on which the calculations were based.

The study adopted a case study approach, and the basic differences in the characteristics of the patient groups served by nurses in the different CDM models made cost comparisons difficult. Moreover, data collected to describe the patient populations served in the different settings were cross-sectional, and information on patient health outcomes was not available. Hence the relative value-for-money of different models could not be assessed. Future research should incorporate a standardised outcome measure, (for example, changes in EQ-5D health state utilities from which QALY changes could be calculated), in order to facilitate comparisons across models.

Prior research has provided partial evidence on the effectiveness of nurse CDM roles included in this study, but has not compared models. Nurse specialists are recognised for the provision of patient-centred care (case management, and education, advice and support to patient and family carers) that is highly rated by their clients (Wilson Barnett and Beech, 1994; Candy, 2007). Primary care nurses have been shown to be effective in case management, CDM, illness prevention and health promotions (Keleher et al, 2009). Evidence also exists that intensive case management of older people by community matrons improves the quality of care (Wright et al, 2007a, 2007b; Leighton et al, 2008), but it has not been shown to reduce emergency hospital admissions (Black, 2007; Clegg and Bee, 2008) or substitute for GPs (Brown et al, 2008).

Further empirical research is required to evaluate in greater depth the work of community matrons, particularly with a view to providing evidence on value-for-money to inform local commissioning and to justify continued investment in their role. Commentaries on the community matron role have indicated a lack of evidence of financial viability (Chapman et al, 2009), tensions between caseload size and quality of care (Sargent et al,

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2008), and the need to establish the 'dose response' of case management (Williams and Cooper, 2008).

Inherent methodological issues make it difficult to measure the effectiveness of nurse roles in terms of clinical outcomes or averted hospitalisations and hence to draw conclusions about cost-effectiveness. To address this problem, it has been suggested that further research should be directed towards identifying specific interventions that nurses employ (Forbes et al, 2006), and that process measures (rather than outcomes) should be used to monitor the quality of clinical practice (Lilford et al, 2007). Tangible features of service input and coordination can be used to assess quality and indicate value-for-money, rather than relying on global standardised measures, which are difficult to collect (Trute et al, 2008). Value-for-money is a measure of good practice, and combines consideration of resource use, costs and quality of service provision (Office of Government Commerce, 2003). It takes account of the appropriateness, timeliness and effectiveness of service inputs in relation to client needs, and includes consideration of costs averted. It may represent a more pragmatic approach to comparing nurse CDM models than cost-effectiveness analysis.

7.5 Summary

There were a number of difficulties and limitations within the economic analysis including uncertainty in the size of caseloads. Most nurses asked to provide activity data were unable to do so due to pressure of work. However, the analysis does indicate that nurse costs per patient are at least ten times higher for community matrons conducting CDM than for nurses working within the other CDM models. The pattern of service utilisation observed in this study is consistent with the focus of the community matron role to provide intensive input and coordinated packages of care that enable this vulnerable group to remain supported in the community setting. However, it is not possible to say how far this higher level of community service provision averts hospitalisations. Similarly, it is not known whether the extra nursing and other health professional input received from community matrons substitutes for GP contact.

The challenges faced within this economic analysis suggests that future research should focus on identifying specific nursing interventions within CDM, and include process measures to monitor the quality of clinical care, and evidence of value-for-money.

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8. Discussion

8.1 Introduction

When this project commenced there was a clear policy focus both nationally and internationally, on the management of LTCs. Rethinking the way CDM was organised was heavily influenced by the chronic care model (Wagner & Groves, 2002; World Health Organisation, 2002; World Health Organisation, 2005). This model is based on the premise that chronic care spans hospital, community and social care organisations and indeed the wider community (Lewis & Dixon 2004) and was drawn upon to inform the long-term conditions model (Department of Health 2005a) (figure 14). We used the four models of service delivery (health promotion; supported self-care; disease management; case management) as part of our sampling frame for the case studies (2.5.3).

As discussed at the beginning of this report, policy approaches have continued to develop during the lifetime of this project and currently there is a national and international focus on the skills practitioners' require for effective working in CDM. In England there is currently a review (Department of Health 2006c, 2007d)of the competencies and training that pre and post registration nurses require to equip them to meet the changing health needs of society. The review is underpinned by a recognition that nurses need to be able to work across sectors but also to bring to those sectors the specific nursing skills required to effectively meet the needs of people with LTCs. A proposed long-term care career pathway for nurses focuses the contribution of nurses on supporting self-care, independent living, personalised care, case management of complex conditions and end of life care wherever care is delivered in collaboration with other health care sectors and appropriate agencies. The nursing role proposed spans the full range of LTCs, covering the life span and includes caring for people with mental health needs and learning disabilities (Department of Health 2007d).

The report introduction highlighted the continual dominance of the systems of health care delivery by the acute care model in which referral to more specialist services or discharge home is often the primary outcome. This can give rise to episodic and fragmented service delivery where service contact is initiated by the patient in response to exacerbations in their condition. In keeping with the acute care model nursing careers historically, have tended to be aligned to departmental or health sector structures rather than to patient caseloads. Patient contact is fragmented as nurses refer onto other nurses in different wards, departments or sectors as the patient moves through the health care system. In contrast the chronic care model promotes the maintenance of an ongoing relationship with the patient by a named health care professional.

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Our systematic mapping of the evidence found duplication and replication within the services designed to meet the needs of patients with LTCs indicating services in transition from the acute model to the chronic disease model, but few that were completely realigned to the chronic disease model. The mapping also found that the amount of 'on the job' training or training to deliver a specific LTC intervention appeared to vary greatly. This ranged from months (Becker 1998, Connor 2002), to days (Forster 1996), to a few hours only (Morgan 2002, Yardley 2004). What was apparent was that although many nurses working in some capacity with patients with LTC had extensive training or experience, this was not always the case, there was often no formal or established training pathway. Our mapping suggested that qualification for many nursing roles tend to depend largely on a nurse's level of clinical experience (Goodwin 2004), although in all our case studies the nurses had undertaken extensive training. However, most experiential learning will have been acquired within an acute care context that is contrary to the principles of care required for LTC, often delaying the implementation of these principles in the daily experience of patients. Further development of educational standards for nurses working within long-term conditions is to be welcomed.

Alongside preparing the workforce, health policies in England are also now focused on integrating LTC services and enabling patient choice and voice in LTC provision and commissioning (Department of Health, 2006d; Department of Health, 2007a; Department of Health, 2007e; Department of Health, 2008a; Department of Health, 2008b; Department of Health, 2008c). The Department of Health states that people with LTCs want services that will support them to remain independent and healthy and have increased choice. In particular, they want seamless, proactive and integrated services tailored to their needs (Department of Health, 2007a). This vision of a seamless patient-centred NHS is underpinned by a quality framework that not only focuses on patient safety and effectiveness of care, but also the patient's entire experience of the NHS (Department of Health, 2008a). Lord Darzi's next stage review of the English NHS (Department of Health, 2008a; Department of Health, 2008c) identified four areas that improved quality would focus upon; helping people to stay healthy, empowering people through rights and control over their own health, improving peoples' access to the most effective treatments, and keeping patients as safe as possible. Central to the review is the notion that patient experience of care that is as personal as possible will be the hallmark of quality. Our findings demonstrate some evidence of transition to the principles of the LTC model particularly in the public health model and community matron model and illustrations

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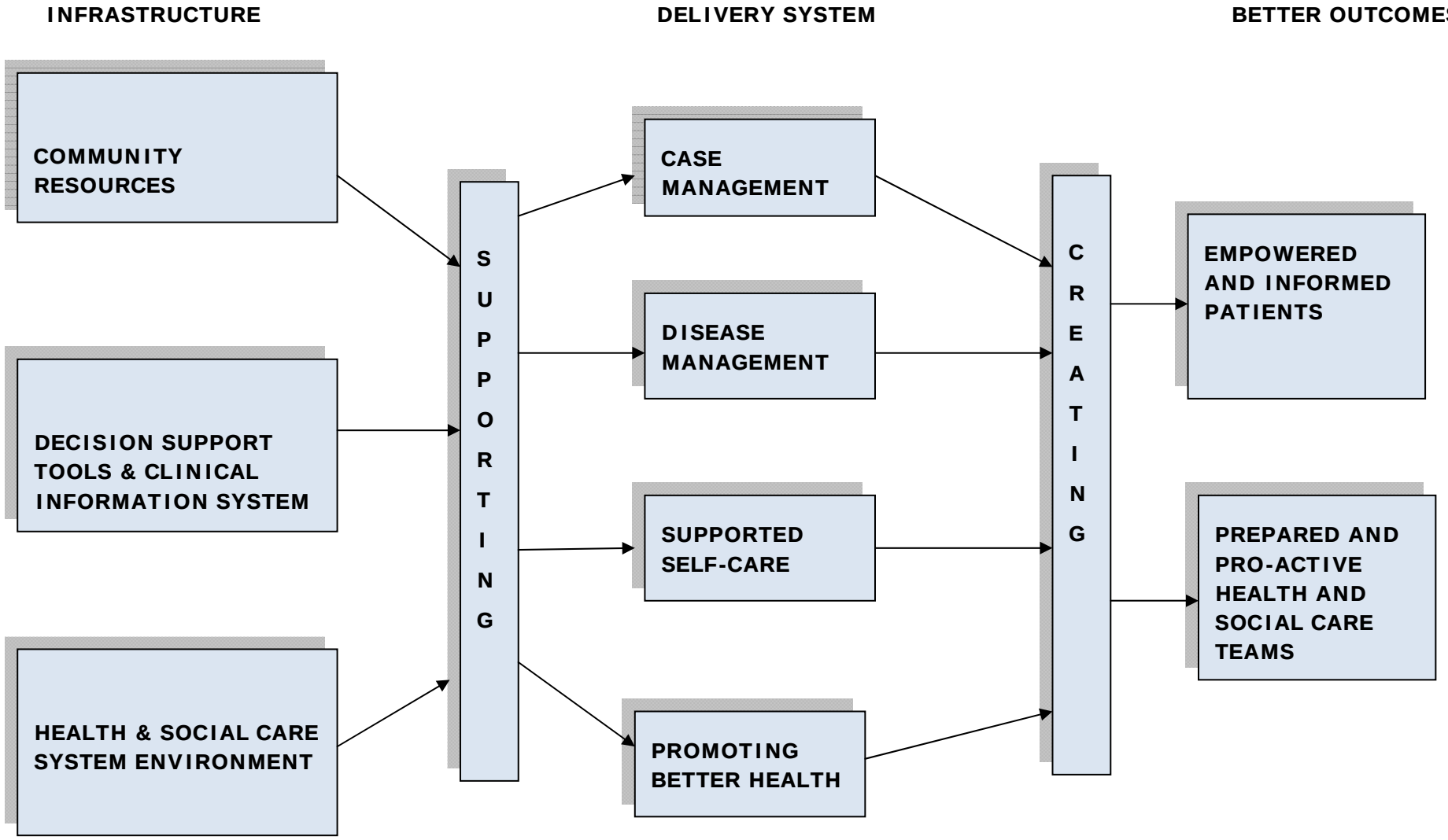
Figure 14 The NHS and social care long-term conditions model (Department of Health 2005b)



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of good practice in both the primary and specialist care model, but implementation remains patchy.

This discussion of our findings will juxtapose our conclusions of the analysis to the policy imperatives highlighted so far. In particular, adopting a whole systems methodology has allowed us to view the nursing contribution to the whole system of CDM through the patient experience. It has also allowed us to identify some barriers and enablers of whole system (integrated) working and some of the challenges nursing must overcome if it is to fully meet its potential in CDM.

8.2 Impact of policy triggers on origins of all models

In each of the case studies the influence of policy triggers on the origin, development and enactment of the nurse's role was evident. However, in only one model (community matron 5.4) was the development a direct consequence of implementing a discrete policy (Department of Health 2005d). The other models were responses to and shaped by a number of policy strategies and contextual triggers, as has been discussed in some detail in the case study analyses. Perhaps what was common to all models was the emergent evidence for the complexity that health care organisations have to grapple with in order to keep up with and respond to policy initiatives. There often appears to be inconsistencies and competition between policies as well as an expectation from government that the commissioning and provision of LTCs management will meet the necessary targets and cost savings. The policy drivers and tensions at the time of the study are summarised as:

- Decentralization – local responses to local need via practice based and PCT commissioning, and the development of Foundation Trusts. Our data suggested that commissioning had reduced some of the scope of hospital based nurse specialists to work across the secondary and primary care interface.
- National Service Frameworks – influenced protocol based care which at times appeared in tension with individualised, patient-centred care.
- Primary and secondary care interface and integrated working – Health and Social Care model for long term conditions (Department of Health 2005a) and the focus on unplanned hospital admissions. At the time of data collection work on pathways of care was only beginning, and there was some evidence to indicate that barriers between primary and secondary care had increased rather than reduced. However, there were some examples of individual practitioners working against the system to reduce barriers.
- Darzi Review (Department of Health 2008a) and other primary care initiatives – performance management against outcomes, QOF, and weighting for deprivation. There was an indication that the QOF

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had shaped the primary care nurse model with some evidence that this was impacting on patient-centred care.

- Patient and public involvement – service user groups and involvement in service development and delivery, patient rights and choice. There is a potential tension between streamlining services for more efficient resource usage versus enabling patient choice (Wilson et al. 2009). Apart from a small sub-set of renal patients in NS2, there was little evidence in the data of service user engagement with service development.
- Public health – health action zones, focus on smoking cessation, obesity and alcohol reduction. A potential tension between focusing on disease management rather than disease prevention was evident from some of our data. However, the Public Health model had an obvious focus on this policy driver and the DESMOND self-management programme in NS2 had a strong component promoting lifestyle change.

Even as this study comes to completion the Department of Health has published "Transforming Community Services" (Department of Health, 2009a) that lays out its vision for a clear distinction between the commissioning and provision of community services that will be guided by a Quality Outcomes Framework for community services, and have local need and patient involvement in service delivery at its heart. Our findings may help to inform the new provider and commissioning arms in relation to the way patients experience long-term condition management and how nursing services can provide this most efficiently.

Despite our initial problems in identifying general practice nurses for the consensus conference, narratives from each of the two primary care nursing sites clearly told a story of expanding nursing roles in response to various initiatives. Amongst these, changes to GP contracts and in particular the 2004 pay-for-performance had led many GPs to increase the numbers of practice nurses and intensified the nurses' work (Gemmell et al. 2009). Although respondents at both sites suggested that the roles had developed in response to local needs and a desire by nurses to expand their role, it was clear that their contribution to the CDM model was shaped by the GP contract. While the QOF is critical in providing funding for practice nurses, the data from patients suggested that at times, the nurse's role was constrained by the need to complete the data recording required as part of the QOF, with clinics running in a pre-structured way rather than in a flexible personalised mode. Some of the nurses were aware of this tension and provided services that went beyond monitoring, such as inviting patients to attend additional clinics or proactively following up patients where indicated, while other nurses worked simply to meet the targets. Patients using the primary care nursing services had the most difficulty naming the nurse, or if they could name the nurse, were the least able to contact the nurse if they had a query, due to the structure of the primary care nurses' working day and week. Of all

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of the models we looked at the primary care nursing model was the one that was least likely to actively work across sectors to address broader non disease specific needs, or to join up with other service providers to address individual or collective patient needs such as education classes or expert patient programmes.

At the time our data were collected, both the primary care nursing and nurse specialist sites were heavily influenced by NSFs and NICE guidelines. The Coronary Heart Disease NSF had had a significant influence on the role of the practice nurse; however practice nurse respondents did not identify other NSFs such as the one for diabetes as having any great impact on the way they worked. While this is unsurprising as the NSF for CHD describes a discrete role for practice nurses whereas the Diabetes NSF does not, it highlights how initiatives such as the NSFs may need to explicitly articulate health professionals' roles to effect any change in working. It may also be the case that the spending review in 2004 which focused on heart disease, stroke and cancer may have also influenced greater change in the way CHD management was approached within primary care. However, the inclusion in the GP contract (Department of Health 2003b) of eleven disease groups including epilepsy and diabetes of which management would be seen as a quality indicator, was equally seen as a trigger in bridging the primary-secondary care gap. The Darzi Review (Department of Health 2008c)provides incentives for practice nurses to further expand their role in CDM and the roll-out of the NHS health check (Department of Health, 2009b) are likely to have a further direct impact on the primary care nursing model. Respondents from the nurse specialist model were more likely to identify NICE guidelines as a lever to improve service provision within their NHS Trust but also highlighted how other policy guidance often reinforced practice that was already commonplace in their area of work. The new QOF for community services (Department of Health, 2009a) will further inform both Primary Care and PCTs in terms of how they develop new approaches to service delivery for LTCs and how best the nursing resource can be used to contribute to quality outcomes.

Evidence of integrated working to provide a public health approach to child hood asthma appeared influenced by policy from other government departments. For example, as discussed in 5.1.5, the DfES have published policy guidance on safeguarding children, the principles of ensuring the health and safety of the whole child through *Every Child Matters (*Department for Education and Skills*,* 2004) and the *National Healthy Schools Standard* (Department for Education and Skills*,* 2005a) has contributed to reducing school absenteeism and improving the health of children by changing the school environment clearly driving the need for the schools asthma strategy. The development of a model led by school nurses was driven by the need to integrate the health needs of young people with asthma with their educational experience and their general well-being in the wider context of school and family life. Underlying the policies and the plethora of guidance published up to the present time around *ECM* is the need to ensure that achievement and behaviour in schools are improved through health-related strategies. This wider goal of

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the public health model for asthma management appeared from our data to be integrated with the more immediate targets of reducing hospital admissions and mortality for childhood asthma.

However, there was also some evidence of unintended consequences of policy initiatives. The emphasis on patient choice and the development of the "Choose and Book" system (Department of Health 2004f) appeared to be having an adverse effect in the epilepsy nurse specialist site, with some health professional respondents arguing that it had removed the possibility of direct clinician to clinician referral, and indeed had also made it difficult for GPs to directly refer to the nurse specialist. Practice based commissioning (Department of Health 2005e) also appeared to be working in tension with the overall aim of cross boundary working in LTC services. A number of practitioners in the nurse specialist models felt that their role in cross sector working as exemplified in the NSFs was being constrained by the effects of practice based commissioning. In some cases primary care organisations were reluctant to refer patients to specialist services in secondary care, and that many services offered by secondary care (for example; DAFNE and DESMOND programmes) to primary care were less likely to be purchased creating inequalities in patient access to specialist services.

Nevertheless, there was a general acknowledgement that the Darzi Review (Department of Health, 2008a) was challenging sectors to relook at the ways they worked together and in thinking outside of the traditional primary to secondary care clinic referral. It was also reported in some of the primary care nursing and community matron sites that changes to the district nursing service was impacting on the model. District nurses have been increasingly seen as an expensive service and since a Value for Money exercise in 1992 (National Health Service Management Executive 1992) the ratio of qualified district nurses within community nursing teams has been reduced. Over the years changes to the organisation of community and primary health care has resulted in a perceived loss of district nursing attachment to GP practices (Goodman 1998). World class commissioning has also influenced the perception of Band 7 qualified district nurses (Department of Health 2006a) as being an expensive provider service to commission, and over recent years there has been a rapid decline in the numbers of qualified district nurses (Drennan and Davis 2008). Ramifications in the case study sites were suggested by reports of deteriorating collaborative working between the primary care nursing model and district nurses, and a lack of supportive working and inappropriate use of skills in the community matron sites. However, although there has been an increase in the number of general practice nurses, there has also been a significant rise of nurses working in the community but without the district nurse qualification. Any perception of a correlation between the rise of general practice nurses and fall in district nurse numbers is more likely to be fuelled by general practice nurses taking over ambulatory or treatment room work previously undertaken by district nurses. In reality the amount of ambulatory care previously

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undertaken by district nurses was likely to be limited but this may feed into perceptions of deterioration in collaborative working.

The importance of including the contribution of school nursing to CDM in childhood has increasingly been recognised, with discussions on how providers and commissioners can use the nursing resource to develop integrated, client focused services. Our data were collected during a period when school nursing was under considerable threat (DeBell, 2006, Storey et al 2007, Christian et al 2005). While there has been international recognition of the work of school nurses in the UK in relation to the Healthy Schools Programme (Department of Education and Skills, 2005), up until very recently the opportunities for school nurses to deliver on their potential for public health work has been seriously compromised by workforce shortages (Drennan *et al*, 2005; Storey *et al,* 2007). The evidence from our analyses contributes to a growing acknowledgement that school nurses can and do operate in a 'navigator' role (Brooks and Kendall *et al*, 2007) in integrating health and education imperatives and that this can be particularly important in managing LTCs for young people.

In conclusion, most of the models arose in response to and were implicitly shaped by policy directives. The community matron model was directly developed out of an explicit policy initiative. Guidelines from NICE were seen as a particularly powerful lever for service improvement but NSFs had varying degrees of influence on the nursing models reported here. From a whole systems perspective the overall policy aims of patient empowerment through choice and information and seamless patient-centred services at times appeared in tension. Many respondents in the nurse specialist and primary care nursing sites felt that rather than removing barriers between sectors, recent policy initiatives were adding some obstacles to both cross-sectoral working and patient access to a full range of services.

8.3 Consequences of pilot working and alternative sources of funding

Three of the case study sites (public health site, nurse specialist site NS2, and community matron site CM2) were distinct from the others in that they had either received pilot or other alternative funding. The public health site had received initial funding from Asthma UK which allowed the model to be tried and tested. Once the worth of the model had been recognised and, as described earlier, with added policy incentives the model had been adopted and embedded within the PCT. In this case study site the initial pilot funding had encouraged the development of relevant, localised and dynamic systems such as the data system. This could be seen as a forerunner of the kind of service delivery envisaged by Department of Health in the recent 'Transforming Community Services' (2009) guidance as it demonstrates recognition of local need, responsiveness to patients and integrated working across sectors as a

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model of service provision. Learning from these locally developed models for future strategic direction in commissioning and providing school health services can be viewed as a significant learning point.

Within the nurse specialist site NS2, the model was enhanced by additional funding gained through research activities. In response to specific local needs the team had developed innovative ways of working and undertook rigorous evaluative strategies funded by research grants. Innovations included the development of the DAFNE and DESMOND self-management programmes which not only provided a service for local patients, but also provided a model transferable nationally and internationally. Again, the additional funding enabled the testing, evidence of effectiveness and subsequent embedding of the model within the local NHS organisation. Once more, this could be described as an example of excellent practice in the transformation of community services, albeit one that challenges the traditional divide between primary and secondary care and is vulnerable to adverse primary care commissioning decisions.

The second community matron site had also received pilot funding for the model to be initially developed, and indeed was situated within a PCT where many new initiatives were being piloted (for example; integrated care pilot, EMIS web pilot). However, as discussed in 4.2.4 many community matrons spoke of the pressure of achieving measurable outcomes such as reducing hospital admissions rather than having other aspects indicative of quality, such as patient experience, taken into account. There was little evidence from this site that the pilot had been embedded into the organisation, and indeed was still being developed alongside a review of district nursing services. This highlights the importance of understanding timeframes when evaluating new service initiatives and the complexity of service transformations required to integrate the different elements of this model effectively. Nationally it has been recognised that the community matron model poses a challenge for the NHS in integrating the case management approach within existing service arrangements (Elwyn *et al.* 2008).

In summary, pilot or alternative sources of funding can provide opportunities for models of CDM to be developed and evaluated. They provide best practice examples for providers and commissioners in the new developments in transforming community services and demonstrate how mutual ways of working might inform innovative service delivery models such as social enterprise. The successful examples also provide evidence of how patient experience of a service can contribute to the overall quality outcome by using their experience to partner with other funding agencies to develop and evaluate the programmes. Problems emerge for the models when the pilot funding is insufficient and fails to allow for a period of embedment into the NHS organisation, or where other priorities take precedence over embedding the model locally.

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8.4 Benefits of the nursing contribution to models of chronic disease management

As discussed in 3.4.5, our mapping of the literature suggested that nurses were seen as more approachable, accessible, and had more time to counsel and educate patients. From the data there would appear to be a range of benefits, some perceived and associated with process, and some more objective measures were observed. In the primary care nursing sites there was some evidence that patients appreciated more local access to services, although this appeared balanced with a persisting belief in a monopoly of expertise within secondary care (see 5.2.2). The nurse specialists were seen as particularly enabling especially during the initial diagnosis period. During this phase of the disease trajectory patients felt vulnerable and often in a state of shock, and the nurses' input were often to help people address their fears through information giving, and enabling people to come to terms with their diagnosis and lifestyle changes. At the end of life phase of the chronic disease trajectory, patients' also viewed the community matron as a "life raft" not offered by other clinicians. Although these patients had accepted there was little medical management available, they found community matrons' input invaluable in helping them to cope with their complex needs. Within the public health model, children and young people had had very little direct contact with the school nurse, and were more likely to have had contact with the practice nurse or GP. However, this was discussed by parents and young people in a context of overall satisfaction with the service both in primary care and school and could be described as a model that provides a seamless approach to asthma care across sectors that is led by school nurses but not necessarily delivered by them. The data did suggest that asthma reviews in primary care could be enhanced further by becoming more adolescent friendly, and as with the adult respondents in the primary care nursing sites, young people spoke of the need for access to specialist services.

All the nurses from the different models described significant effort into educating patients and enabling strategies for self-management. From the patient perspective this was most recognised in the nurse specialist and community matron models, and there was some evidence that there was not enough time available in the primary care nursing model to engage sufficiently in this activity. A recent systematic review also suggests that time in consultations is a major factor in increased patient knowledge and adherence to medication regimens (Keleher *et al.* 2009), and ease of access to a health professional and good information is vital for effective medication adherence (Gordon *et al.* 2007). The relationship between nurse and patient particularly exemplified in the nurse specialist and community matron model is recognised as a key factor in enabling self-management in a long-term condition such as diabetes (Stubbs 2007). Within the public health model there was some evidence suggesting that children (enabled by parents) and younger people were self-managing effectively, but strategies were likely to have been developed over time or learned through family and friends. Despite the development of education

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packs within this model, respondents in this site were unaware of any explicit education, although there was a professional perspective that education and asthma awareness were key components of the asthma strategy. As discussed later, this indicates that the public health model was working in a way that could be considered invisible to children and parents.

There was also some evidence from the patient interview and survey data that symptom management was improved within all sites. In the adult sites this was often enacted by following set protocols and guidelines, but in the public health model this had been enabled by moving beyond normal protocols and providing an emergency inhaler at each school.

The consensus conference revealed that nurses, particularly those working with children and young people, felt one of their main aims was to act as an advocate for groups whose voices were often unheard. Our interview data from health professionals suggested that this was an underpinning philosophy in the public health model, and the impetus of much of the development around the educational packages was to address the needs of young people with asthma who were often marginalised within primary care services. Equally, there was a strong sense in Nurse Specialist site NS1 that a major part of the nurse specialist's role was to advocate for the needs of people with epilepsy, many of whom had learning disabilities. This was highlighted in an interview with a community learning disabilities nurse who gave a number of examples of where the epilepsy nurse specialist had facilitated smooth transition services for her clients, and had developed a countywide education programme enabling learning disabilities nurses to more fully meet the needs of their client population. Service user data also contained examples of how the nurse had advocated for their needs, for example by ensuring they were applying for benefits to which they were entitled. However, it should be acknowledged that the most marginalised groups of service users were difficult to recruit for this study.

Our data suggested that there were a number of nurse-led initiatives within each model. For example; in the public health model a local communications system had been developed by the asthma coordinator to improve communication between schools and practice nurses, and providing a means of tracking activities. While the asthma register of school-aged children was clearly a powerful tool within CDM and fits well with the chronic care model, it does appear that in two of the sites (public health and nurse specialist NS1) such initiatives were dependent on the championing activities of individual nurses, which raises some concerns over succession plans. In the nurse specialist site NS1 it was argued that the model was so deeply embedded that another nurse would be able to carry on this role. However, this site's nurse specialist's profile and the findings of our evidence mapping suggests that success in the role could be more dependent on the individual qualities of the nurse rather than the structure of the role.

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Deeply entrenched in the origins of all the models was a need to reduce demand on other health resources such as doctors' time, costs or hospital admissions. The latter was a clear aim in the community matron, public health and nurse specialist models but our methodology was limited in being able to provide any confirmatory evidence of this. We were told by the sites that anecdotal evidence indicated reductions in hospital admissions and we were told incidents by patients and carers where they attributed prevention of hospital admissions to the nurse; qualitative evidence that is also presented in other studies (Brown *et al,* 2008; Leighton *et al,* 2008). The Asthma UK review of hospital admissions for childhood asthma (Asthma UK 2007, 2008) has shown that the case study site we studied had made major reductions in child emergency admissions since the introduction of the strategy for asthma management. However, our literature review could find little evidence of hospital admission reductions in other areas.

Reduction in hospital admissions as an outcome from LTC services was a major policy driver at the start of this research. However, the early optimism has been replaced nationally with a more nuanced understanding as difficulties encountered in identifying patients at risk of high admission (Billings *et al,* 2006), measuring reductions in hospital admission (Roland *et al,* 2005) and attributing reductions to specific nurse run services have been acknowledged. As described in 4.2.1, participants of the conference were concerned with the lack of clarity around defining a saved admission and the lack of evidence is partly due to the difficulties in measuring this outcome. It is suggested that other indicators such as improvements in physical status, effective liaison with other agencies, and patients and carers acting upon information given to more effectively manage problems should be used as important indicators of the nurse's impact (Elwyn *et al.* 2008).

The shortcomings of the outcome indicators being used nationally at the start of this study were recognised in the initial design of the study. The survey data in this study linked to the qualitative findings were designed to measure patient experience and quality of life as well as service utilisation as suggested by Elwyn *et al* (2008). The findings indicate the potential to benchmark the outcomes of specific service innovations, embedded in the nursing models described in this research, to a broader database of patient outcomes and service utilisation.

For instance, the quantitative analysis indicated that people with epilepsy ($p=0.001$) [site NS1] had a significantly greater EQ-5D score in our study (mean 0.761; sd 0.23) than those in HODaR (mean 0.594; sd 0.38). Patients with diabetes ($p=0.192$) [sites PCN1 and NS2] also had a greater EQ-5D score in our study (mean 0.659; sd 0.33) than in HODaR (mean 0.608; sd 0.32), while those with COPD ($p=0.130$) had a lower EQ-5D score in our study (mean 0.461; sd 0.32) than in HODaR (mean 0.662; sd 0.19) though neither difference was statistically significant.

The quantitative analysis also showed that compared to patients within our study those within HODaR visited the GP more (1.17; sd 1.12;

p=0.050), made more visits to a practice nurse or health assistant (0.90; sd 1.58; p=0.676), and made significantly more visits to an NHS walk-in centre (0.29; sd 1.13; p=0.004), however, they were visited by nurses less (0.68; sd 2.83; p=0.918), visited by other health services the same (0.28; sd 1.33; p=0.753), and visited by social services less (0.53; sd 5.39; p=0.311) within the six weeks prior to survey. HODaR patients also took significantly more time off work (4.95; sd 11.85; p=0.001), significantly more time away from normal activities (9.18; sd 15.10; p<0.001), and needed more care from friends and relatives (9.47; sd 14.92; p=0.383) than patients within our study within the last six weeks.

The survey data also illustrate how expected outcomes from service delivery models can be benchmarked. For instance, of all patients surveyed in our study, nurses had been to visit 0.81 (sd 2.62) times (Appendix 22 table A14), and other health services had been to visit 0.28 (sd 1.00) times (Appendix 22 table A15) in the previous 6 weeks, there were significant differences between site CM1 (Community Matron site) and all other sites (<0.001). This pattern was also seen with regard to being visited by social services (mean 1.07; sd 7.08) (Appendix 22 table A16) with a significant difference betw een site CM1 and the primary care nursing models site PCN1 (p=0.010), site PCN2 (p=0.020), and specialist nursing models site NS1 (nurse specialist) (p=0.008) and site NS2 (p=0.003). These findings reflect expe cted patterns of service delivery for these models and indicate appropriate service input to patient need.

The service transformations described in the nursing models evaluated in this study illustrate the importance of capturing whole system transformation when measuring costs and assessing effectiveness. A recent systematic review (Keleher *et al.* 2009)concludes that nurse-led care is generally no cheaper and indeed may be more expensive than doctor-led care. However, in making comparisons between doctor-led and nurse-led care it is important to include an analysis of the underlying model of care being implemented and the impact of that model on the patient experience. LTC models are designed to transform the way in which services are delivered including the complementary working relationships between different members of the health care team. Greater consideration needs to be given to the roles of different team members within a UK context when implementing LTC models, especially those models imported from other health care policy contexts. Our economic data suggested that large specialist hospital based multi-disciplinary teams produce the least cost per patient, closely followed by the primary care nursing model. Nurses serving more specialist needs of smaller groups of patients as exemplified in the epilepsy nurse specialist model were more costly per patient and patients with complex needs supported by the community matron model produced the highest cost per patient. As indicated in section 7 there are a number of methodological limitations to the economic data which compromise the interpretation of the results. However, the pattern of cost per patient seems to indicate that specialist teams working across large population groups maybe the most cost-effective form of service delivery, although certain LTC, such as epilepsy

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do not lend themselves to this form of health care delivery. Similarly the public health model described in this research would not conform to this approach to costing or delivery. Further work needs to be undertaken on the economic evaluation of these different models in particular a more detailed comparison between the primary care model and the specialist team model. Economic evaluation of the specialist nurse role and the community matron role needs to include a quality of life measure (Vanhook 2007) rather than focus exclusively on cost-savings to other sectors.

There was evidence from all the models that a key contribution of nurses was to enhance self-efficacy and provide psychological support to service users and carers. Participants at the consensus conference and respondents at all the sites identified this as major component of their role and as discussed in 3.4.5, this was echoed in our mapping of the evidence. This benefit was identified by patients in the community matron and nurse specialist models, and to some extent within the primary care nursing model. Children, younger people and parents from the public health model also appeared to be confident in managing asthma although were unlikely to attribute this to any explicit individual nursing intervention. Within the community matron and nurse specialist models, the relationship between nurse and patient appeared fundamental to enhancing self-efficacy, and a major component of this was the ability of the nurses to help patients come to terms with the LTC(s). Accepting threats and changes to self-identity as a result of the chronic disease has been identified as a prerequisite of enhanced self-efficacy (Aujoulat *et al.* 2008), and there was evidence that in the nurse specialist model this was a core activity. In addition, there was some evidence that nurses working within this model and the community matron were actively working towards this before focusing on pre-set targets. This may reflect an acknowledgement that emphasising lifestyle changes to improve physiological outcomes is futile before enabling a positive sense of self (Fisher & Owen 2008).

Promoting self-efficacy through physical and psychological support of the patient and family carer has long featured in theories of health with application to nursing (O'Leary, 1985; Kendall, 1991) which have been subject to considerable controversy about their utility in guiding nursing practice (Tierney 1998, Nolan, et.al. 1998) and have struggled to be implemented in practice (Timmins 2006, Chang et.al 2002, Mawdsley 2005). Our findings suggest, however, how the CDM models described in this research are starting to incorporate some of the features of earlier theoretical models based on a broader evidence base informed by a wider psycho-social and health science literature. This may imply that nursing has the potential to make a theoretical as well as practical contribution to meeting the needs of patients with LTC.

Overall the contribution of nursing to the model of CDM was focused on activities that enabled self-efficacy and dealing with the threats the condition posed. Patients were more likely to recognise this contribution if there had been significant input during times on their trajectory where

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they had felt particularly vulnerable such as initial diagnosis and nearing the end of life phase. Adults, younger people and children during the stable phase of the trajectory were less likely to recognise a discrete nursing input into their care and often described a medicalised approach to their disease management, whereas the more educational and awareness aspects of their management were back-grounded.

8.5 Constraints and contradictions in patient centred care

Our findings from the evidence mapping (3.4.4) identified a number of barriers to an effective nursing contribution within CDM, and these were mirrored in the data. Often the data suggested that there was a lack of understanding about roles, particularly new and emerging roles such as the community matron and asthma coordinator. Within the latter model respondents described how school health advisors would actively refer to GPs and practice nurses but referrals were unlikely to come back. Community matrons also spoke of the initial challenge of promoting their role, echoing other recent research indicating that physicians patterns of referral to nurse case managers were related to perceptions of the nurse's abilities and their previous links with the GP practice (Wilcox *et al.* 2007). The consensus conference also concluded that professional rivalry, particularly when new roles were not understood, was a common and difficult challenge. Equally problematic for those in relatively new roles such as community matrons, was a perceived lack of support and supervision in dealing with the challenges. This anxiety was also reported in the consensus conference and findings from another recent research project suggests uncertainty that community matrons face in meeting caseload targets (Sargent *et al.* 2008).

Patient data identified that in some sites there was sometimes replication of primary and secondary care input and poor communication between the sectors. For example, some patients reported having repeated tests done across sectors. There was, however, one example of a communication tool which patients found very helpful. In nurse specialist site NS2, patients with diabetes and renal failure had access to a website where they could receive up to date information, access all their test results and be able to share these results with clinicians across sectors (Renal Information Exchange Group 2004). These patients were more likely to express a sense of control over their management and describe more active participation in decision making. As this was such a strong recurring theme with these patients, this model of communication would merit further investigation for a broader range of LTCs. However, overall there was a repeating narrative within the literature review, consensus conference and respondent data of incompatible data systems especially between primary and secondary care, and indeed within primary care such as incompatibility of district nursing and general practice systems. In many of the models these issues were being actively addressed, for

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example the community matron site CM2 was a pilot site for the EMIS web system (http://www.emis-online.com/primary-care-systems/emis-web/).

From the patient perspective one of the most significant contradictions in their management was a perception that their most pressing need was not always addressed within review clinics. Some nurses within the primary care nursing model also described difficulties of having to work within systems where the agenda for the consultation was pre-set and there was a focus on discrete disease management rather than being able to address the health priorities identified by the patient. It would seem that while the QOF was enabling a systematic approach to discrete CDM, it was in tension with providing a patient-centred approach congruent with the patient's own prioritised needs. Others have also suggested that the new GP contracts, rather than encouraging a flexible and responsive approach, have tended to increase a bureaucratic approach within general practice (Macdonald *et al.* 2007). However, other models such as the nurse specialist appeared to enable a more flexible approach and there was some evidence from the patient data that they perceived this model was meeting many of their needs beyond exclusively discrete disease management. For example, in both sites respondents described how nurse specialists had helped with employment issues and had provided accessible psychological support, particularly in the early days following diagnosis, to deal with the emotional consequences of living with the LTC. Recent and previous research has suggested that nurses (Rycroft-Malone *et al.* 2009) and in particular nurse specialists (Wilson *et al.* 2006) often find ways to work around protocol-based care to enable a flexible approach in patient-centred care. The case management approach used by community matrons was focused upon meeting the full spectrum of patient needs and this was reflected in the very high levels of satisfaction with this model expressed by patients and carers.

In summary, constraints and contradictions in patient-centred care were often generated by uncertainty around new roles. Issues in communication between and within health care sectors continued to be problematic although there was evidence of new patient information systems being developed that should overcome some of these problems. Communication and data systems that were accessible to cross sector clinicians and patients were found to be a particularly enabling tool for seamless care. However, systematic approaches to disease management such as the QOF also appeared to create barriers to a flexible, patient-centred approach.

8.6 Model patronage and origins of the role

As described earlier, one of the perceived benefits of the nursing contribution to the model was to protect physicians' time, enabling doctors to focus on more complex cases, however these complex cases lack definition. Within the primary care nursing and nurse specialist sites this was a clearly articulated aim, closely entwined with the origins of the nursing models. In these sites the data suggest that the nursing model was actively promoted and in many ways protected by medical patronage.

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For example, in both of the nurse specialist sites the threat to the nurse specialist role following re-grading and financial constraints (Department of Health 2006b), had been described by medical practitioner respondents. Although only substantiated by anecdotal evidence, it does appear likely that these roles were somewhat protected by medical practitioners with relatively strong powerbases.

The community matron sites had not originated in the same way, and as a top down central policy initiative did not have the same level of local patronage. This may make this model more vulnerable and difficult to embed, however if the role becomes substantially viewed by GPs as resource saving it is likely that medical patronage may develop more strongly. Nevertheless, the current situation was that although the nurses within this model felt well-prepared from an education and training viewpoint, lack of support within the local environment could be problematic (Girot & Rickaby 2008).

The public health model differed from the other sites in that the nursing contribution appeared to be based on a relatively strong powerbase of the asthma coordinator. In addition to this powerbase, this model was leading to outcomes that addressed a particular local problem. Traditionally, public health approaches have been associated with nurse-led interventions and evaluations (Kendall, 2008) that have been responsive to both population based need and principles of primary health care. The history of public health nursing in England that includes both health visiting and school nursing, is very different to that of acute and primary care nursing in that the public health role was embedded in local government and not the NHS up until 1974. This had historically stemmed from the 19th century public health movement in Salford and Manchester that was pioneered by the early health visitors, who were not necessarily nurses. There is therefore a history of autonomy and practice that is based on a social model of health that perhaps drives nurses in public health today.

The relative power position between medicine and nursing has changed from one of implicit subjugation (Stein 1967) to one now articulated as a collegial relationship (Allen 1997a, Stein *et al.* 1990). This is evidenced by the creation of a range of new roles including those traditionally seen as medical (Department of Health 2006e, Dowling *et al.* 1996), and encouragement of an NHS culture based on meritocracy (Doyal & Cameron 2000) and rewarded by increasing professional autonomy. Although autonomy is a confused concept (Wade 1999) with interchangeable definitions (Kramer *et al.* 2006, Stewart *et al.* 2004), within this study we define professional autonomy as the ability of particular nurses to make some decisions that are not subject to authorative review by others outside of the profession (MacDonald 2002). Accepting that professions within an institution are interdependent and subject to changes triggered by market demands, specialization and interprofessional competition (Abbott 1988), it is unsurprising that nurses have developed new roles in response to epidemiological and technological changes, and that relationships both interprofessional such as the nurse specialist and doctor, and intraprofessional as with the district nurse and practice nurse

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are in a constant state of flux. While health care continues to be a site for contest and role negotiation (Rafferty *et al.* 2001), apart from the public health site, the models continued to exist within the context of a medical division of labour (Coombs & Ersser 2004, Goldie 1977), where the scope of nursing autonomy is circumscribed at medical discretion (Salvage 2002). Nevertheless, there was some evidence in the nurse specialist sites as well as the public health model, that nurses were not only key players within the whole system, but were attempting to design and develop it too (Forbes & While 2009) and that individual nurses could, through clinical expertise, to some extent earn their autonomy as practitioners in the local system of health care delivery.

8.7 Invisibility of the public health model

Despite an acknowledgement that health visitors are highly skilled in developing public health approaches to CDM (Harrison & Lydon 2008), our literature review and others (Forbes & While 2009) found relatively little evidence on primary prevention of chronic disease. Furthermore we found few unpublished papers, and an internet search plus active snowballing process failed to identify potential health visitor participants for the consensus conference. However, we wanted to include a public approach within our sampling frame as this model was likely to cross a number of sectors and is therefore a clear exemplar of whole system working. We have shown in 5.1 that this approach can enable whole system working and is an effective model of CDM. However, there is a persisting invisibility of the model to service users making it potentially vulnerable to certain models of evaluation and performance indicators.

The user experience from the perspective of both parent and child appears to be that while they are not overtly aware of the school asthma strategy, they have access to a well organised and coordinated service that in its delivery is crossing health and education sectors. This in turn has led to the provision of a seamless service as the awareness and education about asthma in schools has improved (as evidenced by the award of the Asthma Standard to some schools). Medication management is, not surprisingly, important to children and parents but ultimately, as indicated by the findings of Asthma UK, there has been a significant 34 percent reduction in emergency hospital admissions for children with asthma in this area, (Asthma UK, 2008) suggesting that the public health asthma strategy has had an impact on the user experience. The parents and children themselves talked about overall accessibility to asthma services and satisfaction with the way that schools and the health service support the child with asthma. We argue that this 'invisible' service could be attributed to the navigation role of the asthma co-ordinator (Brooks, Kendall *et al*, 2007). Both parents and children seemed confident in the self-management of asthma and this could also be partly at least attributed to the way in which the strategy has increased awareness and brought in challenging techniques such as the emergency inhaler to support children in school.

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8.8 Patient perceptions and expectations

Our mapping of the evidence revealed that while patients and service users viewed nurses as more approachable and accessible, many patients wanted continued access to those they perceived as experts; such as hospital specialists and doctors. This was not a theme reflected in the consensus conference where participants focused on the patient benefit of a nursing input within CDM, however the evidence from the mapping was clearly mirrored in our case study sites. Adult and younger person respondents continued to view the secondary health care sector as the home of medical expertise, and the majority of patient respondents identified the need for access to a specialist. This is in tension with recent policy initiatives transferring a number of acute services to the community (Department of Health 2006d), and was particularly evident in respondents affected by diabetes. These patients, especially those who had been diagnosed some time ago and were more familiar with routine management being provided within an acute trust, were often anxious about levels of expertise in primary care. We found this to be particularly true in nurse specialist site NS2 where many respondents were now receiving care from GP practices rather than the NHS acute trust. In contrast, the majority of patients in primary care nursing sites PCN1 and PCN2 appeared content with the level of expertise they received from the nurses, especially if she/he was an independent prescriber. However in PCN1 site the nurses only managed patients with type 2 diabetes, patients with type 1 diabetes were still referred to secondary care and continued to receive all their support from the local hospital clinic.

Nevertheless, there were three distinct sets of patient perceptions to the nursing contribution within the models. If patients had experienced the nurse within first contact care (Bonsall & Cheater 2008), and had observed the nurse as diagnostician, prescriber and taking on the medical management of the condition, then the patient was likely to view the nurse as the expert and report high levels of satisfaction. However, if the patient was experiencing the nurse in a way they perceived as being the doctors assistant, or had changed from a doctor-led to nurse-led review and management process, then the patient was unlikely to see the nurse as expert and were more likely to continue to consult a GP or hospital specialist if their condition changed or they experienced an exacerbation. Indeed in some cases, particularly the primary care models, the nurse would refer the patient back to the GP or specialist for changes to the treatment regime even when they had successfully identified the problem. A third perception was unique to the public health model, where as described before, there was an invisibility of the contribution and service users were unlikely to comment on any particular value. These different perceptions are illustrated in figure 15. These varying perceptions can also be mapped against the models sampled within this project (figure 16).

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Figure 15 Patient and service user perceptions to the nursing contribution

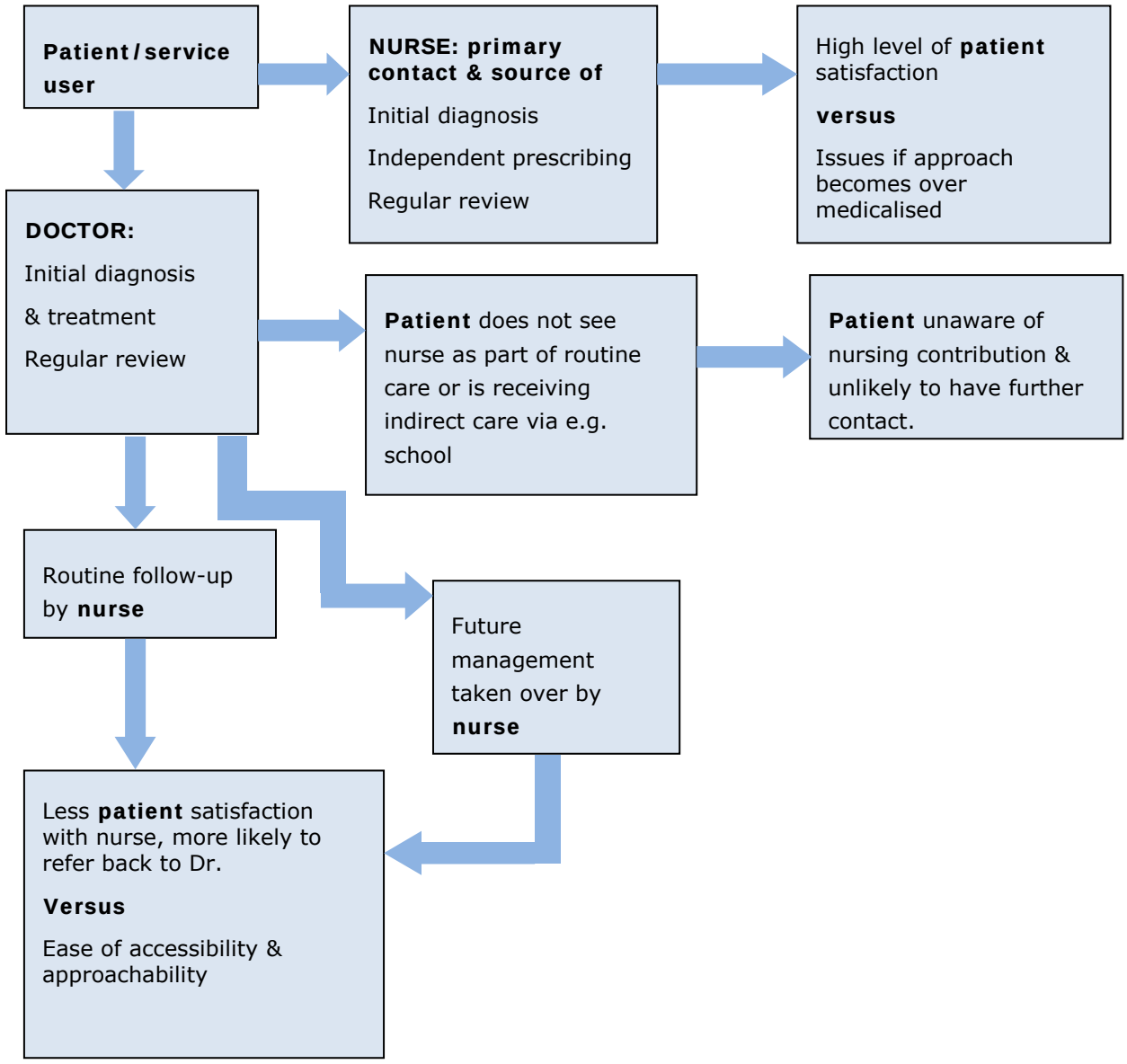

Figure 16 Patient and service user perceptions of models and Outcomes

Fi	rst contact experience[13]	Second contact experience[14]	Third contact experience[15]
Open non-routine access for patient to model (via telephone, email or in person)	Nurse specialist & community matron models	Primary Care Nursing & nurse specialist models	Public health model
Non-routine access to model by patient or clinician initiated appointment	Nurse specialist model	Primary Care Nursing & nurse specialist models	Public health model
Non-routine access to model by referral from other clinician only	Nurse specialist model	Primary Care Nursing & nurse specialist models	Public Health Model

High levels of patient and service user satisfaction with nurses' input

Patient and service user unaware of nursing contribution

[13] We define first contact experience as a patient or service user receiving diagnosis, treatment and on-going CDM from a nurse

[14] We define second contact experience as a patient or service user being referred onto a nurse following initial diagnosis, treatment and CDM from a doctor

[15] We define third contact experience as a patient or service user receiving care or CDM within a system designed and developed by a nurse but with no direct patient contact

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Our data from patients, younger people and parents suggest that the expectation of medical expertise and support for asthma via the GP or practice nurse strongly influences the service user perception of the model. First line contact for children and parents was often general practice but the effect of the strategy on awareness and education in the school environment had the effect that the direct contribution of the asthma co-ordinator and the school nurses was, in the main, invisible to parents. In sites where first contact experience was likely to be in a doctor-patient consultation, respondent discourse often conveyed an image of a clear perspective of the doctor as "my doctor" as opposed to "the nurse". While patients could name their doctor they frequently were unable to name the nurses looking after them and tended to see nurses as interchangeable, even though during the course of the interview some patients realised there were differences in the levels of expertise and quality of the relationship they had with individual nurses. This suggests that continuity of care, going back over a number of years, continues to be a strong predicative of patient satisfaction (Hjortdahl and Laerum, 1992). Respondents that were most positive about the nursing contribution were those who had developed a relationship with a nurse they could name over a period of time, or during periods when they were most vulnerable. Although experiencing first contact care was an important predictive of patient satisfaction with the nursing contribution, so was the personal relationship with the practitioner. Service users felt most positive about nurses with whom they had a good relationship and where first contact diagnostic care was provided. The perception of the nursing contribution in second contact care was boosted if there was ease of accessibility and a good relationship with the nurse. Although respondents were likely to link this relationship with the extra time available for nurse consultations, a recent review found persistent levels of increased patient satisfaction even when controlling for the time variable (Bonsall & Cheater 2008). Ease of contact with named nurses was also a critical factor, with some patients experiencing more difficulty making appointments to see the nurse in primary care, finding it easier to make an appointment with, or speak on the phone to, the GP. This reflects differences in the structure of the GPs' day when compared with the nurses' day which is dominated by pre-booked clinics. It implies that the more complex needs assumed to be the domain of the GP, reflect in fact, patient initiated queries about their care or changes in their condition. It is also indicative of General Practice being an institution designed and governed by GPs (Stacey 1988, Harrison and Ahmad 2000), with continuing control over the division of tasks (Grumbach and Bodenheimer 2004), and workplace values (Abbott 1988).

As can be seen in figure 16, the patient experience of the nurse specialist model was often inconsistent within the sites. Some patients experienced open access to nursing clinics or named specialist nurses whilst others did not and we could not find any particular reasons for this. However, there did seem to be a link between the relationship between nurse and patient, and whether the patient would be enabled to contact the nurse at any time within reason. The limited data set we had for the community

matron suggested that this model was the only one that consistently resulted in open access (albeit not twenty four hours) and first point of contact for the management of their ongoing condition. Here patients could directly contact the community matron about changes in their condition including new symptoms or exacerbations of their existing condition(s) and expect investigations, diagnosis, and initiation of supplementary treatment by the community matron. However, this is unsurprising as this was a key part of the community matron model design from the outset (Elwyn *et al.* 2008).

These findings are of significance because while all the nurses in our sample were highly skilled and competent, patient and service user perception was often guided by what was familiar rather than most appropriate in service delivery. CDM was seen by the vast majority of respondents as a medicalised approach and the nursing contribution was most valued when emulating it, exemplified by the experience of first point of contact for ongoing conditions. Service users who did not experience this were far more likely to continue using health services in a traditional way, such as making a GP appointment for problems to do with the chronic condition when the problem could equally be addressed by the nurse.

In summary, while independent prescribing and other initiatives may encourage patients to use the nurse as the first point of contact for ongoing conditions, there still appears to be a gap between the patient perception and the reality of the nursing contribution to CDM. This gap appears to be linked to the following factors:

- The level of independent autonomy the nurse is able to achieve through;
    - being a named nurse with a distinct and individualised professional identity
    - being an accessible point of first contact for the ongoing management of the LTCs
    - the nurses' availability to respond to being the point of first contact for the patient.
    - the ability and technical facilities to be able to access and input data into a shared patient record.
- The level of clinical expertise achieved by the nurse necessary to earn clinical autonomy through peer review.
- Patronage or support of the role by the local medical elite.
- The ability to work effectively across at least one other sector of provision to meet broader non disease specific health related needs at an individual and group level.

The continued importance of disease specialist clinical expertise to CDM suggests that some aspects of the acute medical model need to be retained and that CDM models act as a governance framework for service provision rather than a distinct professional practice. The role of post-

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registration and CPD education for nursing needs to focus on the development of clinical expertise as well as cross sector working or navigation skills and recognise the critical importance of medical peer review and patronage within the local health sector.

8.9 Limitations of the study

This was an ambitious study that undertook an extensive evaluation of the nursing contribution to a range of CDM models, providing a wide-ranging policy and whole systems analysis. However, there are a number of limitations to the study that need acknowledgement and have an impact on issues of representativeness and generalisibility.

There were a number of methodological issues that could have an important bearing on the validity of the mapping of the literature we undertook. Many of the studies included in the mapping were small, underpowered, and of poor quality with short-term follow up and high rates of attrition. The systematic reviews included in the mapping often gave insufficient detail about the primary studies including the type of interventions and comparators being investigated. There was also a lack of information about the qualifications and experiences of the nurses. In addition, because nurses did not work in isolation but were often part of a multi-disciplinary team or complex system of care it was not always easy to clearly identify, or evaluate the effectiveness of, the nursing contribution.

There were also limitations in our methodology. Although we are confident that the mapping is reasonably comprehensive we are aware that the breadth of the topic means that it is likely that we may have missed relevant studies. In addition, as our aim was to map rather than systematically review the literature, and as we envisaged that a large number of studies would meet our inclusion criteria, we did not undertake a detailed quality assessment of all study types. Therefore, our observations about the effectiveness of the nursing interventions should be interpreted cautiously.

It was slightly disappointing that, although patient satisfaction was generally high, many of the RCTs and systematic reviews did not show the nursing interventions to provide any additional clinical benefits over normal care. This may be because the intervention was ineffective or it may be that these evaluations are too 'blunt' and do not capture the complexity of the nursing contribution, or because the wrong outcomes are being measured. Perhaps this is also an indication of how difficult it can be to change health related risk behaviours, an aim that was central to many of the nursing interventions. One of the reasons we included all study designs, and not just RCTs, was that we felt that non randomised studies might give us greater detail and insight into the nurses' role. However, while this was true of some, many of the weaker study designs gave little in-depth information about the intervention and nurses role.

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It should also be acknowledged that recruitment to the consensus conference was based on a web based scoping of innovative practice, and hence our participants may not have been totally representative of many nurses working within CDM. Equally, as with other studies of this type, we were more likely to recruit the more articulate and informed service user within case study sites.

The numerous practical challenges of undertaking the research, such as NHS research governance, concurrent NHS service reorganisations, and relying on the support of already overworked practitioners, impacted on survey distribution and poor response rates. Although the HODaR questionnaire was based on validated measures and used extensively by CRC Ltd, the wording of some of the questions and the poor response rate contributed to a number of limitations in the economic analysis. Due to limitations in the available data, we were only able to undertake a simple costing exercise to ascertain the per patient cost of the nurse contribution to CDM in each of the models, and to explore patterns of health and social care utilisation. The limitations of the cost analyses are discussed more fully in 7.4.

8.10 Summary

Our research strongly suggests that all the models we sampled were helping people to stay healthy, particularly the public health model. All models put effort into patient education and nurses were key to this activity. Structured education programmes were clearly effective (DAFNE Study Group 2002)in site NS2 but having a large team of nurse specialists and other practitioners enabled this provision. It was more challenging for a single nurse specialist to provide this intensity of education and in site NS1 it was more likely to be on an ad hoc basis. Primary care nurses also clearly articulated their role as containing a strong educative element, but again time constraints and a lack of cross sector working locally appeared to prevent this being provided optimally.

Whilst information and knowledge should improve patient safety, as too should nurses' implementation of evidence based care and treatments, it was interesting to note that there was very little active patient and public involvement in the development of the models. The exceptions to this were the young person involvement in the development of the educational packs in the public health site, and the active renal patient group in site NS2. Many of our nurse respondents recognised this was an area within the model that needed further development.

Our findings indicate that the nursing contribution was key to whole system working. Often in a way invisible to patients and service users, they were the boundary spanners between sectors and organisations, managing to keep the whole system moving despite significant hindrances such as lack of or incompatible data system. This has been described in the literature as 'navigation' by nurses (Brooks, Kendall *et al*, 2007), or as the core nursing function of intermediary (Allen, 2004, 2007b). Identifying the role as such shifts the focus away from unmediated care of service

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users to one where the nurse's relationship to healthcare systems and how their role constitutes contexts of care is central (Allen, 2004). An example from this study is how the nurses managed policy conflicts such as the tension between systematic approaches within the health system and individualised patient centred care. All were highly committed to their models and had chosen to work within CDM which suited their own sense of professional purpose (Mackintosh, 2007).

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9. Conclusions

This project has been conducted during a period where CDM remains a central priority in health care, but where policy has shifted from implementing specific models of CDM to identifying principles of good practice in managing long-term conditions. These principles focus on patient centred approaches, public and community engagement, supporting self-management, integrating services, innovation and improving the quality of patient experience. The study also took place during an evolving period of quality enhancement in the NHS and growing emphasis on providing care closer to home, reducing hospital stay and cost to the NHS (Department of Health 2008c).

Nurses are seen to be at '*the heart of shaping patient experience and delivering care'* (Department of Health 2008a) and are central in providing the type of care patients want; caring and humane, being kept informed and involved, receiving a high standard service, and having timely and convenient access to care (Maben & Griffiths 2008). The evidence from this project provides examples of excellent practice where nurses are actively shaping long-term conditions services, improving quality and making a real difference to patient and service users' lives. Often they were central in enabling a whole system approach but also faced a number of challenges. In the case of adults with long-term conditions, we have undertaken an analysis of cost of the models used. Whilst acknowledging the limitations of our cost evaluation, we have also drawn attention to a useful method of analysing the comparative costs of health care systems. Our finding that the likely higher cost of the Community Matron Model is not surprising in the light of the higher intensity, highly vulnerable patient group to whom this model applies but we were not able to find evidence that the service reduced hospital admission or GP visits. We have drawn on these challenges to make recommendations for commissioners and providers of long-term condition services, practitioners, researchers and policy makers.

9.1 Implications for commissioners and providers

The nurses described within this study were innovative and had developed new ways of working to improve the quality of care. For example; the asthma coordinator in the public health site had spearheaded a cross sector asthma strategy that was making a real difference to the lives of children and young people with the condition. The nurse specialists in both

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sites were constantly developing new ways of working and spanning the boundaries between sectors. The primary care nurses were running well-organised and systematic approaches to CDM and the community matrons were meeting the needs, often against the odds, for the most vulnerable patients. These kind of approaches are at the heart of the vision described by Lord Darzi (McLellan 2009).

The Innovation Fund which each Strategic Health Authority will receive could be put towards innovations that include new ways of service design and culture change as well as new treatments and equipment (McLellan 2009). The evidence from this project suggests that nurses are well equipped to take up this challenge in long-term conditions service delivery and are particularly well placed to develop ways of integrating care. While entrepreneurial nurses may wish to do this via a social enterprise model (Department of Health 2008d), our findings suggest that an organisation that is enabling of innovation and actively seeks funding for initiatives provides an environment where nurses can reach their potential in improving long-term conditions services. Equally important is that new roles and innovations are clearly disseminated, supported and supervised within the organisation, and that it is clearly articulated how the role or service fits and enhances existing provision.

There are persisting difficulties in whole systems working. Our research found that the patient experience often indicates that teams lack integration, for example; the invisibility to the patient of communication between GPs, dieticians, practice nurses and podiatrists about the management of the patient's diabetes. Patients in turn have a persisting belief that specialist expertise can only be found in secondary care (see 8.3) despite the advances in training and skills of those working in primary care based long-term condition services. In all sectors we found evidence that data systems were incompatible where they needed to be compatible, and that patients were recorded as a disease entity. This was particularly problematic for patients with multiple conditions where they found they had to repeat their story over again and the condition that was most significant for them was not always what the practitioner focused on. More flexible approaches to disease management could be developed which allow for patients' holistic and co-morbidity needs to be addressed. This may include thinking about ways of recording and monitoring treatment episodes beyond medical categories.

While innovation should be encouraged our research also revealed that some groups of nurse were unable to meet their full potential in meeting the needs of people with long-term conditions because of changes in service delivery. District nurses were a particular example as their role no longer fitted CDM work in primary care as framed by the QOF for general practice. Equally the constraints of their task focused role did not in general enable an intensive case management approach. Our small sample of patients and family carers who received a nurse case management

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approach described their community nurse (in most cases originally their district nurse) as someone whose care had been good but now was even better. We are aware that current work is underway to develop community services further and our findings suggest many nurses are willing and eager to develop their skills further to meet their full potential in long-term conditions. However, further challenges remain in evaluating the cost of the community matron model compared with other models in relation to outcome, which this study was not able to achieve.

A recurring theme in many of the sites was a lack of knowledge about public involvement in service design. Clearly this is at the heart of current policy (Department of Health 2007b) and it was surprising that the voice of the patient was not being heard at grassroots level. Listening to and engaging with the service user could be further developed by all working within long-term conditions.

9.2 Implications for practitioners

The future professionalism in nursing has been described as nurses having the potential for being practitioner, partner and leader (Maben & Griffiths 2008). All the nurses in this project exhibited these qualities to a greater or lesser extent. First, all had developed a broad range of competencies within CDM. Second, most were exhibiting leadership in developing their services and striving for excellence. Third, all were committed to a one to one or service to public partnership approach. However, this last facet could be developed further and nurses need to learn the skills of listening to and engaging with their whole service user group. Systems for CDM tend to adopt a medicalised approach and we learned from a number of patients the problems of being part of a disease centred system. Often nurses managed to navigate beyond this but a key message from patients is that protocol and disease driven systems may hide patient-identified problems. As suggested in 8.1, ways of approaching CDM beyond a reliance on medical categorization could be explored by nurses.

Current work on developing new career pathways for nurses may address some of the issues nurses working within CDM currently face. A long-term conditions pathway aims to prepare nurses to work across sectors and along illness trajectories of patients across the lifespan (Department of Health 2007d). If implemented, this career pathway would move away from the traditional acute care model, preparing practitioners to provide the type of care envisaged by the long-term conditions model (Department of Health 2005a).

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Invisibility of the nursing contribution to CDM remained an issue in many of our sites. Measuring discrete nursing outcomes continues to be a challenge and on-going work is being undertaken to develop a set of nursing metrics (Griffiths *et al.* 2008). However, early indications are that this work is very acute care focused and nursing must find appropriate ways of measuring effective nursing input within long-term conditions. To date there has been a focus on prevention of unplanned hospital admissions as a measure but while important this gives only a limited view of the patient experience. Other indicators such as effective liaison with other agencies, and patient and family carers effectively acting upon nurse-given information should also be taken into account (Elwyn *et al.* 2008). Using a broader range of indicators could provide a more valid picture of the nurse contribution to long-term conditions management.

9.3 Implications for research and policy

As discussed above, appropriate outcomes for CDM need to be defined and methodologies could be developed that will enable key determinants of the outcomes of CDM to be identified, for example; prospective evaluations that have long-term funding. The importance of whole system working should be identified in the planning of services and well planned cost evaluation/effectiveness studies could be carried out over time that include national quality outcome indicators and measures of patient experience.

Patient experience and patient satisfaction could be mapped so that the conceptual differences between these two related ideas can be demonstrated. A recent European study (Bleich *et al.* 2009) has argued that that only 10 percent of variance in satisfaction surveys is explained by the patient experience and that it is external societal factors that may explain the variation. These authors conclude: 'People's satisfaction with the health care system depends more on factors external to the health system than on the experience of care as a patient. Thus, measuring the latter may be of limited use as a basis for quality improvement and health system reform'. Thus, an appropriate measure of patient experience should be developed that can be used as part of the quality outcome measures.

From a policy perspective investment should be made into changing patient perceptions about the traditional division of labour and the nurses' role. In our study many patients expected their condition to be managed by a doctor and were unfamiliar with the extended and changing role of the nurse in long-term conditions. Therefore, patients appeared unable to make an informed choice about where to seek help for their condition as they did not have the information about what the nurse could offer.

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Further work is also merited on the potential role of the health visitor within chronic disease management, especially from the public health model perspective where there could be real gains from working multi-sectorally as demonstrated through the asthma case study discussed here. From the service user perspective, there appeared a persisting belief of expertise only being found in secondary care which needs to be addressed if long-term conditions are to be effectively managed in primary care. This could be linked to the development of patient accessible websites based on the renal model (Renal Information Exchange Group 2004) where patients can access a range of information, their latest test results and ways of interpreting these.

Policy tensions were also evident in the findings. In particular, the QOF at times appeared in tension with providing a patient centred approach as it resulted in a disease centric approach. Equally, practice based commissioning was resulting in some difficulties in cross health sector working in some sites. Within the new arrangements for transforming community services there should be an investment in different models of service that can best reach different types of populations by understanding the importance of the whole system.

9.4 Recommendations

Commissioners and providers

1. Disseminate new roles and innovations within the organisation, and articulate how the role or service fits and enhances existing provision.

2. Promote the role of the nurses in long-term conditions management to patients and the wider community.

3. Actively engage with the public and service users in shaping long-term conditions services to meet patients' needs.

4. Improve the support and supervision for nurses working within new roles.

5. Develop training and skills of nurses working in the community to enable them to take a more central role in long-term conditions management.

6. Develop organisations that are enabling of innovation and actively seek funding for initiatives that provide an environment where nurses can reach their potential in improving long-term conditions services.

7. Work towards data systems that are compatible between sectors and groups of professionals. Explore ways of enabling patients to

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access data and information systems for test results and latest information.

8. Promote horizontal as well as vertical integration of long-term conditions services.

Practitioners

1. Increase awareness of patient identified needs through active engagement with the service user.

2. Work to develop appropriate measures of nursing outcomes in long-term conditions management including not only bureaucratic and physiological outcomes, but patient-identified and patient-related outcomes.

Implications of research findings

1. Investment should be made into changing patient perceptions about the traditional division of labour, the nurses' role and skills, and the expertise available in primary care for CDM.

2. Development and evaluation of patient accessible websites where patients can access a range of information, their latest test results and ways of interpreting these.

3. Long-term funding of prospective evaluations to enable identification of CDM outcomes.

4. Mapping of patient experience and patient satisfaction so that the conceptual differences between these two related ideas can be demonstrated.

5. Development of appropriate measures of patient experience that can be used as part of the quality outcome measures.

6. Cost evaluation/effectiveness studies carried out over time that includes national quality outcome indicators and valid measures of patient experience.

7. The importance of whole system working needs to be identified in the planning of services.

8. Research into the role of the health visitor in chronic disease management within a public health model.

9.5 Summary

Drawing on the evidence around the challenges nurses' faced when working within the CDM model, a number of implications and

recommendations for commissioners, providers, practitioners, policy makers and researchers are presented.

For commissioners and providers there is some evidence suggesting that nurses are well equipped to develop ways of integrating care, and that organisations focused on enabling innovation may provide a supportive context for these developments. This should be encouraged as the study suggested that there are persisting difficulties in whole systems working when viewed from the service user perspective, and that the voice of the service user is often not heard at grassroots level when planning services.

For practitioners, moving beyond a disease to a person-centred approach in CDM is an important message from service users. The invisibility of the nursing contribution remains a common issue and a broader range of indicators of effective nursing interventions within CDM need to be developed by practitioners and researchers.

Prospective evaluations that have long-term funding are required. These should include full cost evaluation/effectiveness analyses. The relationship between patient experience and patient satisfaction also merits further exploration.

For policy makers there is a need to challenge current public expectations of the nurses' role within CDM. The data suggested that the development and evaluation of patient accessible websites containing information, latest test results and help in interpreting these could be a useful self-management tool for many service users.

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Appendix 1 Search Strategy

Databases searched and search terms used.

PubMed Global Search

(chronic disease OR chronic diseases OR "long-term disease*" OR "long-term illness*" OR chronic[ti]) AND ("Nursing"[MAJR] OR "Nurses"[MAJR] OR "Nursing Care"[MAJR] OR nurs*[ti] OR nurse specialist OR nurse role OR nursing model OR nurse-led OR nurse clinician OR health visitor OR home care OR community care OR nurse-delivered OR domiciliary OR outreach OR primary care OR midwives OR midwifery) AND (trial OR randomi* OR controlled OR qualitative OR themes OR interview* OR study[ti] OR clinical OR psychology OR evaluation OR evidence OR action research OR controlled OR case-control OR cohort OR health service administration OR literature[ti] OR experience OR assessment OR case series OR case management OR managed care OR best practice OR "Research Design"[MeSH] OR "Epidemiologic Research Design"[MeSH] OR "Empirical Research"[MeSH])

PubMed

More sensitive Global search:

(chronic disease OR chronic diseases OR "long-term disease*" OR "long-term illness*" OR chronic[ti] OR "Brain Injury, Chronic"[MeSH] OR "Leukemia, Myeloid, Chronic"[MeSH] OR "Leukemia, T-Cell, Chronic"[MeSH] OR "Leukemia, B-Cell, Chronic"[MeSH] OR "Fatigue Syndrome, Chronic"[MeSH] OR "Leukemia, Myeloid, Chronic-Phase"[MeSH] OR "Leukemia, Lymphocytic, Chronic"[MeSH] OR "Renal Insufficiency, Chronic"[MeSH] OR "Pulmonary Disease, Chronic Obstructive"[MeSH] OR "Hepatitis D, Chronic"[MeSH] OR "Chronic Disease"[MeSH] OR "Leukemia, Myelomonocytic, Chronic"[MeSH] OR "Leukemia, Monocytic, Chronic"[MeSH] OR "Leukemia, Neutrophilic, Chronic"[MeSH] OR "Bronchitis, Chronic"[MeSH] OR "Kidney Failure, Chronic"[MeSH] OR "Brain Damage, Chronic"[MeSH] OR "Multiple Sclerosis, Chronic Progressive"[MeSH] OR "Hepatitis C, Chronic"[MeSH] OR "Pancreatitis, Chronic"[MeSH] OR "Hepatitis B, Chronic"[MeSH] OR "Choreatic Disorders"[MeSH] OR "Huntington Disease"[MeSH] OR "Lymphoma, Small Lymphocytic"[MeSH] OR "Lupus Erythematosus, Discoid"[MeSH] OR "Arthritis, Juvenile Rheumatoid"[MeSH] OR "Irritable Bowel Syndrome"[MeSH] OR "Multiple Sclerosis"[MeSH] OR "Brain Injuries"[MeSH])

AND

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("Nursing"[MAJR] OR "Nurses"[MAJR] OR "Nursing Care"[MAJR] OR nurs*[ti] OR nurse specialist OR nurse role OR nursing model OR nurse-led OR nurse clinician OR health visitor OR home care OR community care OR nurse-delivered OR domiciliary OR outreach OR primary care OR midwives OR midwifery) AND (trial OR randomi* OR controlled OR qualitative OR themes OR interview* OR study[ti] OR clinical OR psychology OR evaluation OR evidence OR action research OR controlled OR case-control OR cohort OR health service administration OR literature[ti] OR experience OR assessment OR case series OR case management OR managed care OR best practice OR "Research Design"[MeSH] OR "Epidemiologic Research Design"[MeSH] OR "Empirical Research"[MeSH])

CINAHL

CINAHL Global Search strategies:

Nurse-Practitioners#.MJ. OR NURSING-ROLE.MJ. OR Nurses#.W..MJ. OR nurse ADJ specialist OR nurse ADJ role OR nursing ADJ model OR nurse-led OR nurse ADJ clinician OR health ADJ visitor OR home ADJ care OR community ADJ care OR nurse-delivered OR domiciliary OR outreach OR primary ADJ care OR midwives OR midwifery

AND

(trial OR controlled OR qualitative OR themes OR interview OR interviews OR study.ti. OR clinical OR psychology OR evaluation OR evidence OR action research OR controlled OR case-control OR cohort OR health service administration OR literature.ti. OR experience OR assessment OR case series OR case management OR managed care OR best practice OR randomised or randomized or randomisation or randomization OR RESEARCH-METHODOLOGY#.DE. OR RESEARCH-NURSING#.DE.)

AND

chronic.TI. OR chronic ADJ diseases OR CHRONIC-DISEASE#.DE. OR long-term.TI. OR chronic ADJ illness

CINAHL Extra: Specific conditions

((Brain OR Haemophilia OR hemophilia OR Fibromyalgia OR endometriosis OR cystic ADJ fibrosis OR Hypertension OR hypertensive OR Back ADJ pain OR Arthritis OR Arthritic OR Chronic ADJ fatigue OR myalgic OR Eczema OR Psoriasis OR Anticoagulation OR anticoagulant$ OR Heart OR cardiac OR Parkinson OR parkinsons OR multiple ADJ sclerosis OR Diabetes OR diabetic OR asthma$ OR obstructive ADJ pulmonary OR COPD OR epilepsy OR epileptic OR neuromuscular).TI. AND 5) NOT 7

((((Stroke OR Sickle ADJ cell OR Scoliosis OR Osteoporosis OR Paget OR pagets OR Crohn OR Crohns OR colitis OR muscular ADJ dystrophy OR Meniere OR menieres OR lymphoedema OR Huntington OR huntingtons OR inflammatory ADJ bowel OR lupus).TI. OR BRAIN-INJURIES#.MJ. OR SPINAL-CORD-INJURIES#.MJ.

OR CEREBRAL-VASCULAR-ACCIDENT#.MJ. OR HYPERTENSION#.W..MJ.) AND 5) NOT 7) NOT 40

AMED, DH-Data, Kings Fund, BNI,

EMBASE, PsycLit

Search 1

(chronic OR chronic ADJ disease OR post-acute OR asthma OR Diabetes OR epilepsy OR cardiac ADJ failure OR heart ADJ failure OR multiple ADJ sclerosis OR arthritis OR spinal ADJ injury OR COPD OR Arthritis OR back ADJ pain OR hypertension OR Inflammatory ADJ bowel ADJ disease OR stoma OR leukemia OR leukaemia OR neuromuscular ADJ diseases OR lupus).TI. AND (nurse.TI. OR qualitative.TI. OR randomised.TI. AND (nurse.TI. OR nurses.TI.) OR (case ADJ management).TI.)

Search 2

(chronic OR chronic ADJ disease OR post-acute OR crohn OR Multiple sclerosis OR Muscular dystrophy OR parkinson OR stroke OR spinal injury OR brain injury OR eczema OR osteoporosis OR renal failure OR sickle cell OR scoliosis).TI. AND (nurse.TI. OR qualitative.TI. OR randomised.TI. AND (nurse.TI. OR nurses.TI.) OR (case ADJ management).TI.)

CINAHL / BNI Extra: Health visitors or district nurses (2003 onwards)

(district ADJ (nurse OR nurses) OR health ADJ (visitor OR visitors)).TI. AND (NHS OR england OR scotland OR wales OR london OR great ADJ britain OR finland OR holland OR United ADJ states OR canada OR netherlands OR chronic.TI. OR long-term.TI.)

NRR

((chronic:ti or long-term:ti) and nurs*:ti)

ERIC

((Keywords:***nurs**** **OR** Keywords:***self*** **and** Keywords:***care***) **and** **(**Keywords:***chronic*** **or** Keywords:***"long term"*** **OR** Keywords:***asthma*** **OR** Keywords:***Arthritis*** **OR** Keywords:***COPD*** **OR** Keywords:***Epilepsy*** **OR** Keywords:***heart*** **and** Keywords:***disease*** **OR** Keywords:***hypertension*** **OR** Keywords:***stroke***))

190 records, screened and selected (RW): 50

NTIS

Chronic AND (nurse OR nurses) title only, since 1990

Cochrane Library

chronic or long-term **in** Record Title **and** nurs* **in** Record Title

WOS

TI=((chronic OR long term OR self care) AND Nurs* NOT cell*)

DocType=All document types; Language=All languages; Databases=SCI-EXPANDED, SSCI, A&HCI; Timespan=1996

TRIP

(Chronic or long-term) AND nurs* (Title only)

SCIRUS

title:chronic AND (title:nurse or title:nurses)

Search terms for refined search

The above searches generated over 12,000 records. To reduce this to a more manageable number we ran a refined search within Endnote. The search terms used were as follows:

Chronic illness OR chronic disease AND nursing or nurse

Chronic illness OR chronic disease AND disease management

Self management OR self care AND nurses

Self management OR self care AND nursing

Nurse-led OR nurse specialist OR community matron* OR practice nurses

Case-management

Health promotion OR health prevention AND nurses OR nursing

Chronic disease AND models AND nurses or nursing

Chronic illness AND models AND nurses or nursing

Long-term AND models AND nurses or nursing

Chronic illness OR chronic disease AND children OR child

Managed care AND nurses OR nursing (all in TI)

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Appendix 2 Conference Brief and Format

Preparation notes

As a delegate you are being asked to make a short presentation about your role in CDM. We hope that the following notes will help you to prepare but if you have any questions please feel free to contact us.

Fiona Brooks, 01707 285994, f.m.brooks@herts.ac.uk

Tricia Wilson, 01707 286391, p.m.wilson@herts.ac.uk

What is the purpose of your presentation?

We are carrying out a national evaluation of nurses, health visitors and midwives[16] contributions to CDM for the Service, Delivery & Organization (SDO) Research & Development Programme (Department of Health). Before we undertake the research element we want to understand the range of roles nurses have in CDM. In particular we want to get a feel of where these roles originated from, what activities they entail, and what kind of outcomes can be expected from these roles. As a consensus conference we hope the presentations will trigger discussion that will enable the identification of common themes. This information will help us plan the next stage of the project and identify case study areas for an in-depth evaluation.

What is the format of the conference presentations?

We aim to make the format as informal as possible to encourage good discussion. The presentations will be held in small groups no larger than 12 people. As a presenter you will have a facilitator present to support you and to record the key points of the discussion. Wherever possible the groups will be made up of people in similar areas of work such as condition-specific roles. We hope to include in each group a service user representative and a service manager who have agreed to participate in the discussion.

How should presentations be delivered?

Ideally the presentations should be made in powerpoint and be emailed to p.m.wilson@herts.ac.uk no later than **8th September**. If you would prefer to use

[16] To avoid repetition we will from now on just refer to nurses but within this include health visitors and midwives.

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an overhead projector then please let us know as soon as possible so that we can make sure the appropriate equipment is in the room.

What should be the content of your presentation?

We would like the presentation to have three sections.

1. How did your role in CDM originate? For example did your role originate from a specific identified need in your geographical area, or did it originate because other health care professionals could not meet the need? Alternatively your role may have originated from a "top down" policy initiative, or indeed may be a mix of a number of factors.

2. What activities does your role in CDM include? Does this reflect your job specification or are you focusing on one or more particular elements? You may want to illustrate this part of the presentation with an example of an innovation you may be involved in or alternatively a picture of a typical day/week.

3. What are the outcomes of your role in CDM? In particular we would welcome any results of audits, outcome research you have undertaken or any evidence that illustrates the outcomes.

What is the timing of the presentation?

The presentation should be no longer than **10 minutes**. The facilitator will then allow about 5 minutes for questions. At the end of all the presentations there will be about 40 minutes to draw up a consensus of the key themes. The actual time slot for your presentation will be given to you on the day but the earliest presentation will be at 11.15.

What will happen after the conference?

We will draw together all the key themes and send each delegate a summary. The themes will be used to help us identify the kind of case study sites and outcomes we should be looking for in the research phase of the evaluation.

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Appendix 3 Consensus conference follow-up workshop data form.

Name:	Position:

Data collection We are planning to use the following tools for data collection: HoDaR questionnaire Health Utilization questionnaire Stanford six item self-efficacy scale for chronic disease	**Will these tools be easy to use and appropriate for your client group ?**
Data collection We also want to collect cost data	**Do you know what current mechanisms are in place to measure costs in your area of work?**
Data collection We will want to interview key stakeholders, service users and clients as part of the study	**Who do you consider to be the key stakeholders?** **Will there be any particular challenges in interviewing service users and carers in your caseload?**
Data collection	**Is there any other data that you would consider essential when evaluating the nursing**

We do not wish to omit any data that are seen as important	**contribution?**
Access to data In order to collect these data we need to be able to access them	**Who would we have to approach in your area (post title) for access?** **Do you know whether your research & development department are used to external research being carried out?** **Do you know of any other research or evaluations that are currently being carried out around your role?**
Quantity of data We need to know how much data each case study are likely to provide so that we can use sampling processes if necessary	**How large is your caseload?** **How long have you been in your current post?** **Is this a fixed term post or is the post likely to be there over the next 2 years?**

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Case study site We are defining a case study site by the model (for example, active case management) being used. We need to know how many people are involved in this model in the case study site.	**Do you work on your own or are part of a multi-disciplinary team?** **Do you work in or lead a team of nurses? If so how many are there in the team?**

Appendix 4 Adult patient interview schedule

Patient interview guide

1. Tell me a little about yourself, are you married, do you work?

2. Tell me about your condition? What condition(s) do you have and when did you find out about them?

3. Are you able to look after yourself? How do you manage your condition(s) on a daily basis? What are the main difficulties you face?

4. Is there anything you need help with?

5. What are your main concerns?

6. What help has been provided from health and social services?

7. (Note: will need to clarify the difference between the two with the participant)

8. Was the help provided useful? Did it meet your needs? Does it address your main concerns?

9. Does your illness/es affect your family? How does it affect them?

10. Could your family do with more help, information or support? If so what would help them OR "what could be provided that isn't?"

11. Which health & social care professionals do you deal with? Who has been most helpful, and have you experienced any problems?

12. What part do nurses play in your care if any? What nurses do you see? How helpful have they been?

    Probes
    a. What issues do you just talk to the nurse about?
    b. Does the nurse just talk to you about your one medical condition (e.g. diabetes) or do they talk to you about any other condition or concerns you have?
    c. What issues do you think are better discussed with a doctor?
    d. How often do you see the nurse?
    e. Where do you see the nurse?
    f. Do you arrange the appointment or does the nurse?
    g. Are you involved in the notes she makes about your consultation?
    h. What kind of information does the nurse give you when you see them?

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Appendix 5 Family carer interview schedule

Family carer interview guide

First, a little bit about yourself:

How old are you?

Do you or did you work – if so what do/did you do?

1. What do you think are the main care needs of your (patient)?

2. How long have they had these needs?

3. How well are they (patient) able to look after themselves?

4. Is there anything the person you care for needs help with?

   Probes
   a. How much time per day do you spend caring for …
   b. What does this involve for you?

5. What are your main concerns about them?

6. What is your health like? Do you have health care needs? How do you manage your own health?

   Probes
   a. Are you able to have time away from your carer role & responsibilities?

7. Tell me a little about yourself such as do you also do paid work and how long you have been caring for…

8. What help has been provided from health and social services?

   (Note: will need to clarify the difference between the two with the participant)

9. Was the help provided useful? Did it meet the main needs of the person you care for? Does it address your main concerns?

10. What about other members of the family, do they provide support? (Siblings etc –try to get at if the family is supported in an holistic fashion – this may not be appropriate for all)

11. Which health & social care professionals do you deal with?

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12. Who has been most helpful? (Probe why? How?)

13. Have you experienced any problems?

14. What part do nurses play in the care of …… What nurses have you seen and how does the nurse help you if at all? What care do they provide if any? How helpful have they been?

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Appendix 6 Parent interview schedule

Parent interview guide

1. What do you think are the main care needs of your (child)?

2. How long have they had these needs?

3. How well are they (child) able to look after themselves?

4. What are your main concerns about them?

5. What is your health like? Do you have health care needs? How do you manage your own health?

6. Tell me a little about yourself such as any paid employment you have?

7. What help if any has been provided from health and social services? (Note: will need to clarify the difference between the two with the participant).

8. How helpful if at all has the school been?
    a. Has the school nurse been any help?

9. Was the help provided useful?
    a. Did it meet the main needs of your child?
    b. Did/ Does it address your main concerns?

10. What about other members of the family, do they provide support? (Siblings etc –try to get at if the family is supported in an holistic fashion – this may not be appropriate for all)

11. Which health & social care professionals do you deal with?
12. Who has been most helpful? (Probe why? How?)
13. Who has been the least helpful? (Probe why? How?)
14. Have you experienced any problems?
15. What part do nurses play in the care of ……
16. What nurses have you seen
    a. How does the nurse help <u>your child</u> at all?
        i. Probe about different nurses in different contexts? (PHC setting compared to hospital and school nursing)
    b. How does the nurse help <u>you</u> if at all?

17 What care do they provide if any? 18. How helpful have they been?

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Appendix 7 Young person interview schedule

Young People Interview Schedule

Theme 1 Having a long-term condition

Q1. Tell us about what it is like in an average day with your condition?

Probes differences between
a) at school
b) at home/with parents and siblings
c) with friends

Q2. What sort of things do you do to keep yourself healthy?

Probes
a) different strategies
b) difference between actual practices and what they feel they should be doing

Q 3. What helps you to feel better?

- Probe any difference between physically feeling better and emotional well being (feeling happier in yourself)

Theme 2 help and support

Q4. Who are the people who give you help in coping with your condition?

Probes
a) Parents
b) Friends
c) Siblings
d) Teachers
e) Health professionals (which ones?)

Q5. Explore the help given from the following –
a) GP
b) Nurse in the community clinic /GP practice
c) Nurse who might visit you at home
d) Hospital doctors
e) Hospital nurses
f) Other professionals such as Physiotherapist

Q6. How do health staff talk to you when you se them?
a) Who makes decisions about care? About medicines (ask for examples)
b) Do you have a say in decisions that are made? (probe are they asked for their views and feelings?)
c) Medicines – are they talked to about side effects? Are they listened to?
d) Do they feel they are asked too many questions?

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e) Do they feel staff are kind and understanding (probe is their privacy respected)

Q7. Do health staff ever help you by sorting out problems/issues you might have with other adults? Probe parents and schools

a) Do they help you to talk to other adults such as parents and teachers about your condition?
b) Do they ever talk to other adults for you?
c) What about helping you with friends or siblings?

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Appendix 8 Health professional interview

Clinician / manager interview guide

Nurses only :

First, a little about yourself.

a) How long have you been in your current post?
b) What qualifications do you have?
c) What locality do you cover?
d) GP practices you link with?

1. Tell me about your role in X…. (describe your role)

   Probes
   a. In which setting do they see patients
   b. Type of contact with patients
   c. Ratio of practitioner initiated contact with patient versus patient initiated contact
   d. Average amount of time spent with a patient each year
2. Where did your/this particular role originate from?

   Probes
   a. Who initiated it?
   b. Was there any problems/difficulties in setting it up?
   c. What was the thinking behind it/rationale for it?
   d. Has the team changed since the role originated?
3. What have been some of the challenges of this role?

   Probes
   a. Accessing clinical supervision/support
   b. Level and type of admin support
   c. Liaison with other professionals
4. What have been some of the joys (positives) of this role?

   Probes
   a. Accessing clinical supervision/support
   b. Level and type of admin support
   c. Liaison with other professionals
5. What appears to have helped in making the role more effective?

6. Which new policies (central or local) appear to have had the most impact on the role?

7. What type of training/experience & preparation have you/they had and what seems to be most helpful?

   Probes
   a. In-service training
   b. Higher education courses
   c. other
8. What (if any) unique contribution does a nurse bring to the role?

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9. With which disciplines are there the most overlap in this role?

10. From the patient/user perspective what advantages are there for a nurse to lead this role?

11. How much patient involvement is there?

    Probes
    a. Patient-held records
    b. Engagement with user groups

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Appendix 9 Young person focus group schedule

Theme 1 Having a long term condition

Q1. Tell us about what it is like in an average day with your condition?

Probes differences between
a) at school
b) at home/with parents and siblings
c) with friends

Q2. What sort of things do you do to keep yourself healthy?

Probes
a) different strategies
b) difference between actual practices and what they feel they should be doing

Q 3. What helps you to feel better?

a. Probe any difference between physically feeling better and emotional well being (feeling happier in yourself)

Theme 2 help and support

Q3 Who are the people who give you help in coping with your condition?

Probes
a) Parents
b) Friends
c) Siblings
d) Teachers
e) Health professionals (which ones?)

Q4 Explore the help given from the following –
a) GP
b) Nurse in the community clinic /GP practice
c) Nurse who might visit you at home
d) Hospital doctors
e) Hospital nurses
f) Other professionals such as Physiotherapist

Q5 How do health staff talk to you when you se them?
a) Who makes decisions about care? About medicines (ask for examples)
b) Do you have a say in decisions that are made? (probe are they asked for their views and feelings?)
c) Medicines – are they talked to about side effects? Are they listened to?
d) Do they feel they are asked too many questions?

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e) Do they feel staff are kind and understanding (probe is their privacy respected)

Q6 Do health staff ever help you by sorting out problems/issues you might have with other adults? Probe parents and schools

a) Do they help you to talk to other adults such as parents and teachers about your condition?
b) Do they ever talk to other adults for you?
c) What about helping you with friends or siblings?

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Appendix 10 Adult survey.

ut You

- What is your **Year** of birt
- What is your height? feet hes **OR** cm
- What is your weight? lb **OR** kg
- What is your waist size? inches **OR** cm

eight 5 y

Decreased a lot | Decreased a little | No change | Increased a little | Increased a lot

Yes No

- Do you smoke?

If yes, how many per day?

Yes No

If no, have you ever smoked?

- How long have you been/were you a smoker? Years
- On average, how many units of alcohol do you drink each week? Units

one unit = a glass of wine *or* half pint of beer *or* one spirit measure

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Please tick your occupation.

If you have **retired,** please mark the box that best describes your occupation prior to your retirement:

Professional	☐	Unskilled	☐
Skilled non-manual	☐	Never employed	☐
Skilled manual	☐	employed	☐
Non-skilled manual	☐	Full-Time education	☐

~~How much physical activity you do~~

The following is a question on how much exercise or physical activity you normally do. This includes things like walking, gardening, cycling and *~~any activity that makes you slightly warm and breath harder than usual.~~*

Please read the statements and tick the one that best describes you

I usually exercise every day	☐
I usually exercise 4-6 times per week	☐
I usually exercise 2-3 times per week	☐
I usually exercise once a week	☐
I usually exercise every 2-3 weeks	☐
I usually exercise about once a month	☐
I never take exercise	☐

On the whole

I think I do enough exercise	☐
I don't think I do enough exercise	☐
I think I do too much exercise	☐

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What illnesses do you receive treatment for? (*Please list below)*

- _____
- _____
- _____
- _____
- What is your ethnic group?

Please choose ONE section from A to E, then place a ☒ in the appropriate box to indicate your cultural background.

A. White

British W (please circle one) ☐
Welsh /English /Scottish W ☐
Irish ☐
Any other White background ☐

B. Mixed

hite and Black Caribbean ☐
hite and Black African ☐
White and Asian ☐
Any other Mixed background ☐

C. Asian or Asian British

ian ☐
tani ☐
Bangladeshi ☐
Any other Asian background ☐

D. Black or Black British

Caribbean ☐
African Any ☐
Any other Black background ☐

E. Chinese or other ethnic group

Chinese ☐
other background ☐

If any other background from sections A to E, please state:

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Your General Health

On a scale of "**1**" (**WORST** possible health) to "**100**" (**BEST** possible health), how would you rate your health today?

How do you think your nurse specialist/case manager has changed your health (please tick one box):

Much improved	Improved	No change	Worse	Much worse
☐	☐	☐	☐	☐

Your Health Today

- **Mobility ***
  - I have no problems in walking about ☐
  - I have some problems walking about ☐
  - I am confined to bed ☐
- **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 ☐
- **Pain or Discomfort**
  - I have no pain or discomfort ☐
  - I have moderate pain or discomfort ☐
  - I have extreme pain and discomfort ☐

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- **Usual 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 ☐

- **Anxiety or Depression**

  I am not anxious or depressed ☐

  I am moderately anxious or depressed ☐

  I am extremely anxious or depressed ☐

* Please tick this box if you use a wheelchair. ☐

Health Related Events

1. Questions about the medication you receive

a. How many different types of prescribed tablets or other medicines are you taking per day ? ☐☐

b. How often do you forget to take your tablets or other medicines ?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

c. If you take tablets or medicines, do you feel you have any benefit from them ?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

Service Use

1. How many times have you seen a GP in the last six weeks ? ☐☐

2. How many times have you been to visit a practice nurse or health care assistant in the last six weeks ? ☐☐

3. How many times have you been to a NHS Walk-in Centre or contacted NHS Direct in the last six weeks ? ☐☐

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4. How many times have any nurses been to visit you in the last six weeks ?

5. How many times have you been visited by other health services staff in the last six weeks, e.g. health visitor, physiotherapist or chiropodist ?

6. How many times have you been visited by social services staff in the last six weeks, e.g. social worker or home help ?

7. How many days have you had to take off paid employment in the last six weeks ?

8. Other than paid employment, how many days have you had to spend away from your normal activities, e.g. gardening, housework, in the last six weeks ?

9. How many days have friends or relatives needed to care for you or help you with your normal activities in the last six weeks ?

10. How many times have you stayed overnight in hospital in the last 6 months related to one of your illnesses listed above?

11. How many nights have you spent in hospital over the past 6- months related to one of your illnesses listed above? (*enter total number of days)*
(*If necessary prompt:* '

And what about the time before that?')

Your Health and Well–Being

For each of the following, please mark an ☒ in the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
▼ ☐	▼ ☐	▼ ☐	▼ ☐	▼ ☐

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2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf……..	☐	☐	☐
b. Climbing several flights of stairs…..…….....	☐	☐	☐

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the	None of the time
a. Accomplished less than you would like…….	☐	☐	☐	☐	☐
b. Were limited in the kind of work or other activities……..……...	☐	☐	☐	☐	☐

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the	None of the time
a. Accomplished less than you would like…….	☐	☐	☐	☐	☐
b. Did work or other activities less carefully than usual..……..……...	☐	☐	☐	☐	☐

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5. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼ ☐	▼ ☐	▼ ☐	▼ ☐	▼ ☐

6. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks…..

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a. Have you felt calm and peaceful?……	☐	☐	☐	☐	☐
b. Did you have a lot of energy?……	☐	☐	☐	☐	☐
c. Have you felt downhearted and depressed?…..	☐	☐	☐	☐	☐

7. **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities like visiting friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼ ☐	▼ ☐	▼ ☐	▼ ☐	▼ ☐

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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.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

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 ?

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

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 ?

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

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 ?

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

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

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

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 ?

not at all confident ? ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ *totally confident*

1 2 3 4 5 6 7 8 9 10

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Appendix 11 Young Person Survey

Thank you for helping us with this survey. By answering these questions you will help us to find out more about the way that young people live in England live, their health and their illnesses.

Your answers will be looked at by the survey study team and by no-one else. They will NOT be seen by your parents and teachers. There is no need to write your name on the questionnaire. After you have filled it in, you can put it in the envelope provided and seal it.

In most questions you will be asked to place a cross in the box that best fits your answer, for example:

Do you like football? **Yes** ☐

No ☒

In other questions, a line is given where you can write your answer.

Some of the questions contain instructions telling you which question to answer next. Following these instructions means that you won't have to answer any questions that don't apply to you. For example:

Do you like football? **Yes** ☐ **Go to question 12**

No ☒ **Go to question 18**

Take your time to read each question carefully in turn and answer it as best you can. Please go on to the next question unless you are instructed otherwise.

Remember that we are only interested in your opinion – this is not a test.

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About you

1. Are you a boy or a girl?

Boy ☐

Girl ☐

2. What year are you in?

Year 7 ☐ Year 10 ☐

Year 8 ☐ Year 11 ☐

Year 9 ☐ Post 16 ☐

3. What month were you born?

January	☐	May	☐	September	☐
February	☐	June	☐	October	☐
March	☐	July	☐	November	☐
April	☐	August	☐	December	☐

4. What year were you born?

1989	☐	1993	☐
1990	☐	1994	☐
1991	☐	1995	☐
1992	☐	1996	☐

5. Father **Mother**

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Does your father have a job?

Yes ☐
No ☐
Don't know ☐
Don't have or don't see father ☐

Does your mother have a job?

Yes ☐
No ☐
Don't know ☐
Don't have or don't see mother ☐

If NO, why does your father not have a job?

(Please cross the box that best describes the situation)

He is sick, or retired, or a student ☐

He is looking for a job ☐

He takes care of others, or is full-time in the home ☐

I don't know ☐

If NO, why does your mother not have a job?

(Please cross the box that best describes the situation)

She is sick, or retired or a student ☐

She is looking for a job ☐

She takes care of others, or is full-time in the home ☐

I don't know ☐

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6. What is your ethnic group?

We need to know this so that we make sure we are including young people from all groups in school in our survey.

Please cross one box only.

A. White		**B. Mixed**		**C. Asian or Asian British**	
British	☐	White & Black Caribbean	☐	Indian	☐
Welsh /English /Scottish	☐	White & Black African	☐	Pakistani	☐
Irish	☐	White & Asian	☐	Bangladeshi	☐
Any other White background	☐	Any other Mixed background	☐	Any other Asian background	☐

D. Black or Black British		**E. Chinese or other ethnic group**	
Caribbean	☐	Chinese	☐
African	☐	Any other background	☐
Any other Black background	☐		

If any other background from sections A to E, please state:

……

……

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7. Food and drink

How many times a week do you usually eat or drink…….?

Please cross one box for each line

	Never	Less than once a Week	Once a week	2-4 days a week	5-6 days a week	Once a day, every day	Every day, more than once a day
Fruits	☐	☐	☐	☐	☐	☐	☐
Vegetables	☐	☐	☐	☐	☐	☐	☐
Sweets (including chocolate)	☐	☐	☐	☐	☐	☐	☐
Coke or other soft drinks that contain sugar (not diet drinks)	☐	☐	☐	☐	☐	☐	☐
Any alcoholic drink	☐	☐	☐	☐	☐	☐	☐

8. At the moment are you on a diet or doing something else to lose weight?

Please cross one box only:

No, my weight is fine ☐

No, but I should lose some weight ☐

No, because I need to put on weight ☐

Yes ☐

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Physical Activity:

Physical activity is any activity that increases your heart rate and makes you get out of breath some of the

time.

Physical activity can be done in sports, school activities, playing with friends, or walking to school.

Some examples of physical activity are running, brisk walking, rollerblading, cycling, dancing, skateboarding, swimming & football

For these next two questions, ADD UP ALL THE TIME you spend in physical activity each day.

9. Over the past 7 days, on how many days were you physically active for a total of at least 60 minutes per day? (Add up all the time you spend each day)

Please cross one box only

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 days 1 2 3 4 5 6 7

10. Over a typical or usual week, on how many days are you physically active for a total of at least 60 minutes per day? (Add up all the time you spend each day) *Please cross one box only*

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 days 1 2 3 4 5 6 7

11. How many computers and video consoles does your family own?

Please cross one box for computers and one box for video consoles

	Computers	Games consoles (eg Playstation/XBox)
None	☐	☐

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One ☐ ☐

Two ☐ ☐

More than two ☐ ☐

12. Do you have your own bedroom for yourself? ***Please cross one box only***

Yes ☐

No ☐

13. How many days each week are you involved in each of these particular kinds of club or organisation (eg youth club, swimming/athletics club, choir, dance group etc.) ***Please cross one box only***

Every day of the week ☐ Once or twice a week ☐

5- 6 days a week ☐ Less than once a week ☐

3 or 4 days a week ☐ Not at all ☐

14. How much say do you have when you and your parents are deciding how you should spend your free time outside school? ***Please cross one box only***

I usually decide how I spend my free time outside school ☐

My parents and I decide, but I usually can do what I want ☐

My parents and I decide, but I usually do what my parents want me to do ☐

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My parents usually decide ☐

15. How do you and your friends decide what to do together?

Please cross one box only

I usually decide what we will do ☐

My friends and I decide equally what we do ☐

My friends and I decide, but usually I do what my friends suggest ☐

One of my friends usually decides ☐

16. During the past 12 months, how many times did you travel away on holiday or with your family? *Please cross one box only*

Not at all ☐

Once ☐

Twice ☐

More than twice ☐

17. Does your family own a car, van or truck? *Please cross one box only*

Not at all ☐

Yes, one ☐

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Yes, two or more ☐

Smoking and drinking:

18. Have you ever smoked tobacco? (At least one cigarette, cigar or pipe) Please read all of the following sentences carefully and cross the box next to the one which you think you are the most like.

I have never smoked ☐

I have only ever tried smoking once ☐

I used to smoke sometimes, but I never smoke tobacco now ☐

I sometimes smoke now, but not as often as once a week ☐

I smoke at least once a week, but I don't smoke every day ☐

I smoke every day ☐

19. How often do you smoke tobacco at present? Please cross one box only

Every day ☐

At least once a week, but not every day ☐

Less than once a week ☐

I do not smoke ☐

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20. At present, how often do you drink anything alcoholic, such as lager, beer, wine or spirits like vodka and gin? Try to also include those times when you only drink a small amount. *Please cross one box for each line*

	Every day	Every week	Every month	Rarely	Never
Alcohol	☐	☐	☐	☐	☐

21. Have you ever had so much alcohol that you were really drunk?

Please cross one box only

No, never ☐

Yes, once ☐

Yes, 2-3 times ☐

Yes, 4-10 times ☐

Yes, more than 10 times ☐

Your school:

22. How do you feel about your school at the moment? *Please cross one box only*

I like it a lot ☐

I like it a bit ☐

I don't like it very much ☐

I don't like it at all ☐

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23. In your opinion, what do your teachers think about your school performance compared to your classmates? ***Please cross one box only***

Very good ☐

Good ☐

Average ☐

Below average ☐

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Bullying:

Remember – all the answers you give are confidential and no one at school or home will see your answers

Here are some questions about bullying. We say a student is BEING BULLIED when another student, or a group of students, say or do nasty and unpleasant things to him or her. It is also bullying when a student is teased repeatedly in a way he or she does not like or when they are deliberately left out of things. But it is NOT BULLYING when two students of about the same strength power argue or fight. It is also not bullying when the teasing is done in a friendly or playful way.

24. How often have you been bullied at school in the past couple of months?

Please cross one box only

I haven't been bullied by another student(s) at school in the past couple of months ☐

It only happened once or twice ☐

2-3 times a month ☐

About once a week ☐

Several times a week ☐

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Your friends:

25. At present, how many close male and female friends do you have?

Please cross one box each column

Males		Females	
None	☐	None	☐
One	☐	One	☐
Two	☐	Two	☐
Three or more	☐	Three or more	☐

26. How many days a week do you usually spend time with friends right after school?

Please cross one box only

	☐	☐	☐	☐	☐	☐	☐	☐
Evenings	0	1	2	3	4	5	6	7

27. How often do you talk to your friend(s) on the phone or send them text or email messages? *Please cross one box only*

Rarely or never	☐
1 or 2 days a week	☐
3 or 4 days a week	☐
5 or 6 days a week	☐
Every day	☐

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Your family:

28. Now we'd like to ask you about who you live with.

Not everyone lives with both their parents. Sometimes people live with just one parent, sometimes they have two homes or two families.

Please fill in column A for your main or your only home.

Fill in column B if you have a second home (not including holiday or summer houses).

A Please put a cross in the box for all the people who live in your house.		**B** Please put a cross in the box for people who the people who live in your house.	
ADULTS:		ADULTS:	
Mother	☐	Mother	☐
Father	☐	Father	
Stepmother (or father's girlfriend)	☐	Stepmother (or father's girlfriend)	☐
Stepfather (or mother's boyfriend)	☐	Stepfather (or mother's boyfriend)	☐
Grandmother	☐	Grandmother	☐
Grandfather	☐	Grandfather	☐
I live in a foster home or children's home	☐	I live in a foster home or children's home	☐
Someone or somewhere else: *please write it down*		Someone or somewhere else: *please write it down*	
……		……	
……		……	

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CHILDREN:

Please say how many brothers and sisters live here including half, step or foster brothers brothers and sisters.

Please write in the number or write 0 (zero) if there are none.

How many brothers? ☐

How many sisters? ☐

CHILDREN:

Please say how many brothers and sisters live here including half, step or foster and sisters.

Please write in the number or write 0 (zero) if there are none.

How many brothers? ☐

How many sisters? ☐

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Remember – all the answers you give are confidential and no one at school or at home will see your answers

29. How easy is it for you to talk to the following persons about things that really bother you?

	Very easy	Easy	Difficult	Very difficult	Don't have or see this Person
Father	☐	☐	☐	☐	☐
Stepfather (or mother's boyfriend)	☐	☐	☐	☐	☐
Mother	☐	☐	☐	☐	☐
Stepmother (or father's girlfriend)	☐	☐	☐	☐	☐

	Very easy	Easy	Difficult	Very Difficult	Don't have or see this person
Elder brother (s)	☐	☐	☐	☐	☐
Elder sister (s)	☐	☐	☐	☐	☐
Best friend	☐	☐	☐	☐	☐
Friends of the same sex	☐	☐	☐	☐	☐
Friends of the opposite sex	☐	☐	☐	☐	☐
A nurse	☐	☐	☐	☐	☐
A doctor	☐	☐	☐	☐	☐
A social worker	☐	☐	☐	☐	☐

About you and your health:

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30. Would you say your health is……? *Please cross one box only*

Excellent ☐

Good ☐

Fair ☐

Poor ☐

31. How much do you weigh without clothes?

☐ Stones ☐ lbs

Or ☐ Kg

Don't know ☐

32. How tall are you without shoes?

☐ eet ☐ nches

Or ☐ m ☐ cm

Don't know ☐

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EVERYBODY TO ANSWER:

33. In the last 6 months: how often have you had the following…….?

Please cross one box for each line

	More than once a every day	About every week	About every month	Rarely or never	About
Headache	☐	☐	☐	☐	
Stomach-ache	☐	☐	☐	☐	
Back ache	☐	☐	☐	☐	
Feeling low	☐	☐	☐	☐	
Irritability or bad temper	☐	☐	☐	☐	
Feeling nervous	☐	☐	☐	☐	
Difficulties in getting to sleep	☐	☐	☐	☐	
Feeling dizzy	☐	☐	☐	☐	

34. Here is a picture of a ladder

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The top of the ladder '10' is the best possible Life for you and the bottom '0' is the worst possible life for you.

In general, where on the ladder do you feel you stand at the moment?

Cross the box next to the number that best describes where you stand.

35. In general, how do you feel about your life at the moment?

Please cross one box only

I feel very happy ☐

I feel quite happy ☐

I don't feel very happy ☐

I'm not happy at all ☐

36. **What illnesses do you receive treatment for?** *(Please list below)*

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_____

_____

_____

_____

_____

37. Please tick this box if you use a wheelchair. ☐

38. Questions about the medicines or pills you are taking

a. How many different types of tablets or other medicines that you get from your doctor (not vitamins) are you taking each day? ☐☐

b. How often do you forget to take your tablets or other medicines?

All of the time	Most of the time		A little of the time	None of the time
☐	☐	☐	☐	☐

39a. If you take tablets or medicines, do you feel they are doing you good?

All of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐

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39b. If you are feeling well do you "leave off" or stop taking your inhalers?

Yes ☐ No ☐

40. Service Use

a. How many times have you seen a family doctor /GP in the last six weeks?

b. How many times have you been to see a nurse at the GP surgery in the last six weeks?

c. How many times have you seen a nurse in a clinic about your condition in the last 6 weeks?

d. How many times have any nurses been to see you at home in the last six weeks?

e. How many times have you been seen by other health workers in the last six weeks e.g. health visitor, physiotherapist or chiropodist?

f. How many times have you been seen by social services staff in the last six weeks e.g. social worker or care assistant?

41. How many days have you had to take off school or college in the last <u>6 weeks</u>? ☐

a. Apart from school or college, how many days have you not been able to do your normal activities, e.g - swimming, football, clubs and other hobbies in the last **6 weeks**? ☐

b. How many days have your parents or carers needed to help you with your daily routine such as getting dressed or washing in the last **6 weeks** ? ☐

c. How many times have you stayed overnight in hospital in the last **6 months** ☐

because of one of your illnesses?

d. How many times have you been to an Accident and Emergency department

(at the hospital) for one of your illnesses in the last **6 months**? ☐

42. Have you been in pain at any time during the last 6 weeks?

None	Mild	Severe	Very severe
☐	☐	☐	☐

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43. During the past 6 weeks, how much did pain stop you from doing everyday activities such as sports, hobbies AND/OR daily routines?

Not at all	Sometimes	Most of the time	All the time
☐	☐	☐	☐

44. During the past 6 weeks, how much of the time has your physical health or emotional problems stopped you from doing your social activities (like seeing friends, clubs, going out etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

HBSC: Health Behaviour in School-aged Children: A World Health Organization collaborative cross-national study.
For more information see: www.hbsc.org

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Part 2.

If you have an illness such as asthma, diabetes or cystic fibrosis you should also complete part 2 please.

Adolescent's Self-Efficacy Scale

For each question, put a tick (✓) in the box (□) that describes YOU the best.

1. I can find ways to stop my condition making me feel sad.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

2. I can find ways to stop my condition making me feel lonely.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

3. I can find ways to stop my condition making me feel annoyed or fed-up.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

4. I can manage my symptoms so that I can take pleasure from the things that I enjoy.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

5. I can control my condition at school.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

6. I can control my condition when I am doing school games or PE.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

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7. I can control my condition when I am with my friends.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

8. I can control my condition when I go out with my family.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

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Appendix 12 NRES approval

Appendix 12. NRES Approval

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25 April 2007

Professor Sally Kendall
Professor of Nursing and Director of the Centre for
Research in Primary and Community Care (CRIPACC)
University of Hertfordshire
CRIPACC, University of Hertfordshire
College Lane, Hatfield
Herts AL10 9AB

Dear Professor Kendall

Full title of study: **Evaluating the nursing, midwifery and health visiting contribution to models of chronic disease management**

REC reference number: **07/Q1602/33**

Thank you for your letter of 11 April 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 24 April 2007. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.3	22 February 2007
Investigator CV		07 February 2007
Protocol	2	02 April 2007

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Covering Letter		19 February 2007
Letter from Sponsor		06 November 2006
Statistician Comments		15 February 2007
Questionnaire: Teenage health survey	n/a	
Questionnaire: Adult survey	n/a	
Participant Information Sheet: Young person focus group	1	15 February 2007
Participant Information Sheet: Teenager questionnaire	1	15 February 2007
Participant Information Sheet: Health professional interview	2	02 April 2007
Participant Information Sheet: Under 10 focus group	2	02 April 2007
Participant Information Sheet: Parent young person	2	02 April 2007
Participant Information Sheet: Parent under 10 focus group	2	02 April 2007
Participant Information Sheet: Parent interview	2	02 April 2007
Participant Information Sheet: Adult patient questionnaire	2	02 April 2007
Participant Information Sheet: Adult patient interview	2	02 April 2007
Participant Information Sheet: adult carer interview	2	02 April 2007
Participant Consent Form: Young person focus group	2	02 April 2007
Participant Consent Form: Parent under 10	2	02 April 2007
Participant Consent Form: Parent interview	2	02 April 2007
Participant Consent Form: Adult questionnaire	2	02 April 2007
Participant Consent Form: Adult participant interview	2	02 April 2007
Participant Consent Form: Carer interview	2	02 April 2007
Participant Consent Form: Health professional interview	2	02 April 2007
Response to Request for Further Information		11 April 2007
Young person parent interview invitation letter	1	15 February 2007
Child parent invitation letter	1	15 February 2007
young person parent invitation letter	1	15 February 2007
young person focus group invitation letter	1	15 February 2007
Young person first invitation letter	1	15 February 2007
health professional invitation letter	1	15 February 2007
adult part interview invitation letter	1	15 February 2007
adult part 2nd questionnaire invitation letter	1	15 February 2007
Adult part 1st questionnaire invitation letter	1	15 February 2007
Parent interview schedule	1	15 February 2007
Child & Ad focus grp schedule	1	15 February 2007
Under 10's flowchart	1	15 February 2007
Adolescents flowchart	1	15 February 2007
Adult flowchart	1	15 February 2007
Letter from funder		11 November 2005
Cert of liability insurance	01/08/06 - 31/07/07	01 August 2006
Health prof interview schedule	1	15 February 2007
Informal carer interview schedule	1	15 February 2007
Patient interview schedule	1	15 February 2007
Assent form children under 10	1	15 February 2007
Adult carer invitation letter	2	02 April 2007

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R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final approval from the R&D office before commencing any research procedures.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1602/33	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Professor Nigel Wellman
Chair

Email: scsha.BerksREC@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
Standard approval conditions

Copy to: Sponsor - Prof John Senior
University of Hertfordshire
College Lane
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Hertfordshire
AL10 9AB

Appendix 13 NRES first amendment

Appendix 13. NRES First Amendment

National Research Ethics Service
Berkshire Research Ethics Committee
Building L27
University of Reading
London Road
Reading
RG1 5AQ

Tel: 0118 918 0556
Fax: 0118 918 0559

16 July 2007

Professor Sally Kendall
Professor of Nursing and Director of the Centre for
Research in Primary and Community Care (CRIPACC)
CRIPACC, University of Hertfordshire
College Lane, Hatfield
Herts AL10 9AB

Dear Professor Kendall

Study title:	**Evaluating the nursing, midwifery and health visiting contribution to models of chronic disease management**
REC reference:	**07/Q1602/33**
Amendment number:	**1**
Amendment date:	**20 June 2007**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 12 July 2007.

Ethical opinion

The members reviewed the amendment form and submitted documentation and were happy to approve changes to the recruitment process.

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	3	20 June 2007
Invitation letter	2	20 June 2007
Notice of Substantial Amendment (non-CTIMPs)	1	20 June 2007
Covering Letter		28 July 2007

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

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R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1602/33:	**Please quote this number on all correspondence**

Yours sincerely

Ms Lavenda Lee
Assistant Co-ordinator

E-mail: scsha.berksrec@nhs.net

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: Prof John Senior, University of Hertfordshire

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An advisory committee to South Central Strategic Health Authority

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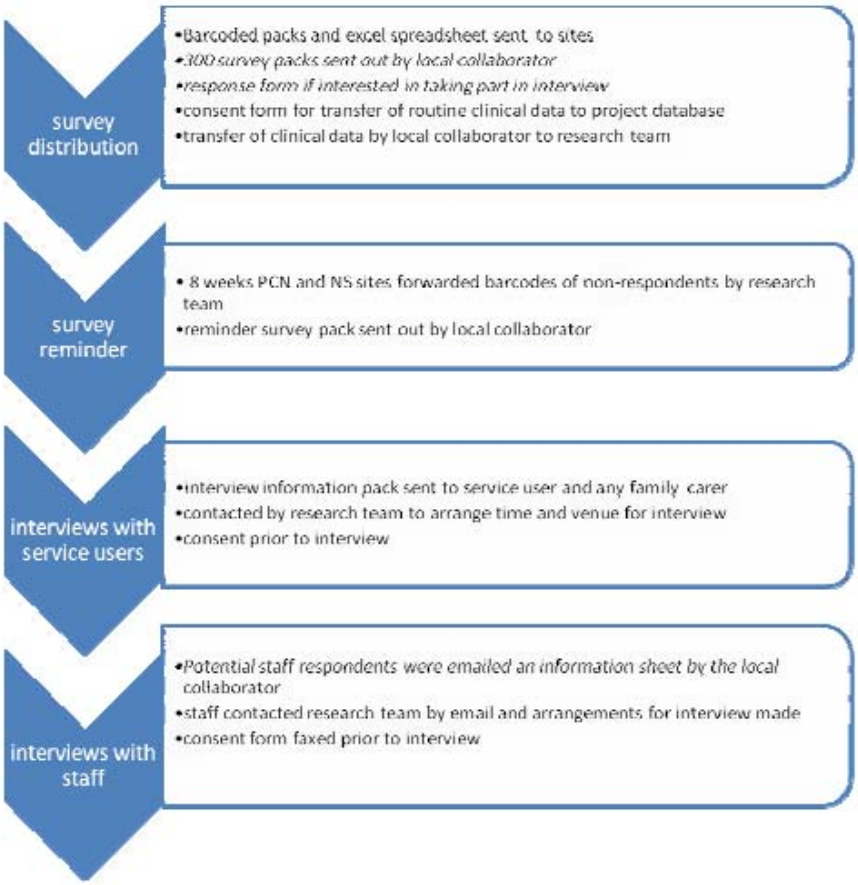
Appendix 14 Recruitment process in adult case study



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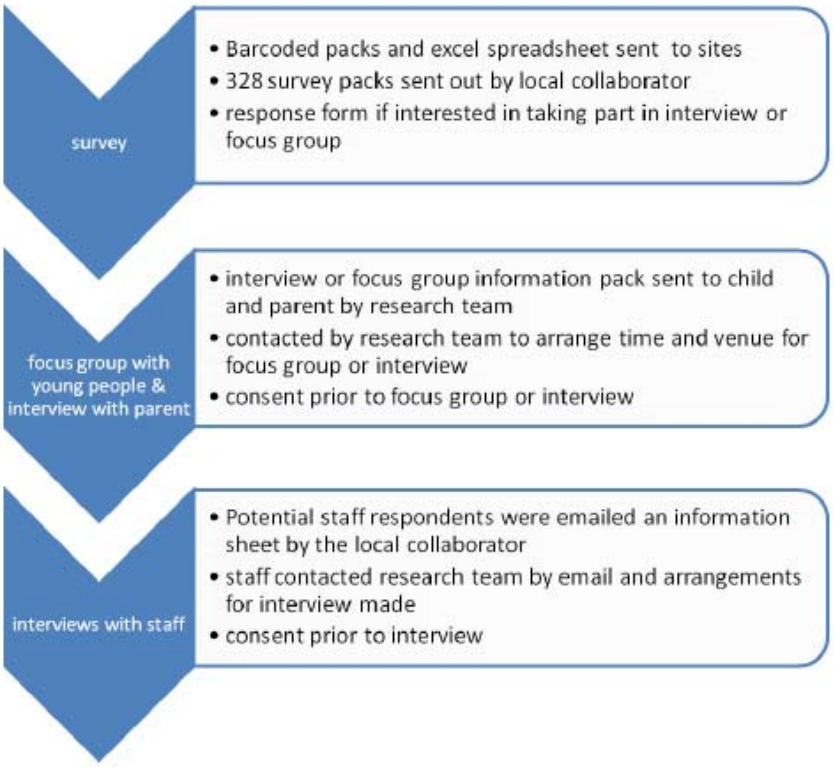
Appendix 15 Recruitment process in younger person case study sites



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Appendix 16 NRES second amendment

Appendix 16. NRES Second Amendment

National Research Ethics Service
Berkshire Research Ethics Committee
Building L27
University of Reading
London Road
Reading
RG1 5AQ

28 September 2007

Tel: 0118 918 0556
Fax: 0118 918 0559

Professor Sally Kendall
Professor of Nursing and Director of the Centre for
Research in Primary and Community Care (CRIPACC)
CRIPACC, University of Hertfordshire
College Lane, Hatfield,
Herts. AL10 9AB

Dear Professor Kendall

Study title: **Evaluating the nursing, midwifery and health visiting contribution to models of chronic disease management**
REC reference: **07/Q1602/33**
Amendment number: **2**
Amendment date: **17 September 2007**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 25 September 2007.

Ethical opinion

The members reviewed the amendment form and submitted documentation and were happy to approve changes to the data collection methods. The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Yong person interview	1	17 September 2007
Participant Information Sheet: Parent young person interview	1	17 September 2007
Participant Consent Form: Young person consent interview	1	17 September 2007
Young person interview schedule	1	17 September 2007
Notice of Substantial Amendment (non-CTIMPs)	2	17 September 2007
Covering Letter		17 September 2007
Protocol	4	17 September 2007

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Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1602/33:	**Please quote this number on all correspondence**

Yours sincerely

Ms Lavenda Lee
Assistant Co-ordinator

E-mail: scsha.berksrec@nhs.net

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: Prof John Senior, University of Hertfordshire

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Appendix 17 NRES third amendment

Appendix 17. NRES Third Amendment

NHS

National Research Ethics Service

Berkshire Research Ethics Committee

Building L27
University of Reading
London Road
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RG1 5AQ

15 January 2008

Tel: 0118 918 0556
Fax: 0118 918 0559

Professor Sally Kendall
Professor of Nursing and Director of the Centre for
Research in Primary and Community Care (CRIPACC)
University of Hertfordshire
College Lane, Hatfield
Herts. AL10 9AB

Dear Professor Kendall

Study title: **Evaluating the nursing, midwifery and health visiting contribution to models of chronic disease management**
REC reference: **07/Q1602/33**
Amendment number: **3**
Amendment date: **26 November 2007**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 15 January 2008.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Under 10 asthma focus group	3	26 November 2007
Participant Information Sheet: Young person focus group	2	26 November 2007
Participant Information Sheet: Parent young person	3	26 November 2007
Participant Information Sheet: Teenager questionnaire	2	26 November 2007
Participant Consent Form: Young person focus group	2	26 November 2007
Notice of Substantial Amendment (non-CTIMPs)	3	26 November 2007
Covering Letter		17 December 2007
Protocol	5	26 November 2007
Participant Information Sheet: Parent interview	3	26 November 2007
Participant Information Sheet: Parent under 10 focus group	3	26 November 2007
Participant Consent Form: Parent interview	3	26 November 2007

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Participant Consent Form: Parent under 10	3	26 November 2007
Young person asthma services invitation letter	1	26 November 2007
Young person interview invitation letter	2	26 November 2007
Assent form for children	2	26 November 2007

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

R&D approval

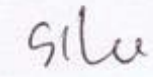
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q1602/33:	**Please quote this number on all correspondence**

Yours sincerely



Ms Lavenda Lee
Assistant Co-ordinator

E-mail: scsha.berksrec@nhs.net

Enclosures — List of names and professions of members who were present at the meeting and those who submitted written comments

Copy to: — Prof John Senior, University of Hertfordshire

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Appendix 19 Quality Assessment Tables.

Table a: Systematic Review Quality Assessment

Study ID	Clearly focused question	Description of methodology	Literature search sufficiently rigorous	Study quality is assessed & taken into account	Enough similarities between studies to make combining them reasonable	Overall score
Cardiovascular						
Gustafsson 2004	Adequately addressed	Poorly addressed	Adequately addressed	Poorly addressed	N/A	-
Hamner 2005	Adequately addressed	Poorly addressed	Adequately addressed	Poorly addressed	N/A	-
Page 2005	Well covered	Well covered	Well covered	Well covered	N/A	++
Phillips 2005	Well covered	Well covered	Well covered	Adequately addressed	Adequately addressed	++
COPD / Respiratory						
Ram 2004	Well covered	Adequately addressed	Poorly addressed	Adequately addressed	Adequately addressed	+
Smith 2001	Well covered	Poorly addressed	Adequately addressed	Adequately addressed	Adequately addressed	+

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Taylor 2005	Well covered	Well covered	Well covered	Adequately addressed	Adequately addressed	++
Dermatology						
Courtenay 2006	Poorly addressed	Poorly addressed	Adequately addressed	Not addressed	N/A	-
Diabetes						
Loveman 2003	Well covered	Well covered	Well covered	Well covered	N/A	++
Epilepsy						
Bradley 2001	Well covered	Well covered	Well covered	Adequately addressed	N/A ++	
Health Promotion						
Rice 2004	Well covered	Well covered	Adequately addressed	Well covered	Adequately addressed	++
Hypertension						
Oakeshott 2003	Poorly addressed	Not reported	Not reported	Poorly addressed	Poorly addressed	-
MS						
De Broe 2001	Well covered	Adequately addressed	Poorly addressed	Adequately addressed	N/A +	
Forbes 2003	Well covered	Well covered	Well covered	Adequately addressed	N/A ++	
Not condition specific						

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Frich 2003	Adequately addressed	Well covered	Adequately addressed	Well covered	N/A	++

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Table b: Randomised Controlled Trials Quality Assessment

Study ID	Date	Allocation concealment*	Blinded outcome assessment (Yes/No/not clear)	Intention to treat analysis (Yes/No/not clear)	80% or more followed up (Yes/No)	Study size (number randomised)
Anticoagulation						
FitzMaurice 2000	2000	B	Unclear	Yes	Yes	224
Asthma						
Abdulwadud 1999		B	Unclear	Unclear	No	125
Castro 2003		A	No	Yes	No	96
Griffiths 2004		B	Yes	Yes	Yes	324
Greineder 1999		B	Unclear	Unclear	No	57
Salisbury 2002		B	Yes	Yes	Yes	450
Yang 2005		B	Unclear	Unclear	Yes	62
Madge 1997		C	Unclear	Unclear	No	201
Hughes 1991		C	Unclear	Unclear	Yes	95
Pinnock 2003		A	Unclear	Yes	Yes	278
Morice 2001		C	Unclear	Unclear	Yes	80
Levy 2000		B	Yes	Yes	Yes	211
Smith 2005		B	No	Yes	Yes	92
Persaud	1996	B	Unclear	No	Yes	36
Premaratne 1999		B	postal	no	No	Not clear
Kamps 2003		B	Unclear	Unclear	Yes	74
Bowel Disease						
Smith 2002		A	Unclear	No	Yes	
Cardiovascular						
Allen 2002		B	Unclear	Yes	No	228

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Barth 2001	B	Unclear	Unclear	No	34
Koelling 2005	B	Unclear	Unclear	Yes	223
Thompson 2005	B	Yes	Yes	No	106
Morgan 2002	B	Yes	Yes	No	3001
Murchie 2003/ 2004	B No		Yes	Yes	1343
Lloyd-Williams 2004	B	Unclear	Unclear	No	235
Mejhert 2004	B	Unclear	Yes	No	208
DeBusk 2004	C	Yes	Yes	Yes	462
Jerant 2001/ 2003	A Yes		Yes	Yes	37
Jolly 1999	B	Yes	Yes	Yes	597
Quist-Paulsen 2003	A	Unclear	Yes	Yes	240
Dougherty 2004	B	Unclear	Yes	Yes	168
Carlsson 1997	B	Unclear	Unclear	Yes	168
Ekman 2003	A	Unclear	Yes	Yes	145
COPD / Respiratory					
Coultas 2005	B Yes		Unclear	No	217
Kwok 2004	C	Yes	Unclear	Yes	157
Wong 2005	B	Yes	Yes	Yes	60
Dermatology					
Chinn 2002	B	Unclear	Yes	Yes	
Gradwell 2002	A	Unclear	Yes	Yes	
Diabetes					
Ko 2004	C	No	Unclear	Yes	180
Krein 2004	B	Yes	Yes	Yes	246
Howe 2005	B	not clear	Unclear	Yes	89
Litaker 2003	B	Yes	No	No	157
Gary 2003	B	Yes	Yes	Yes	186
Gabbay 2006	C	Unclear	Unclear	No	332
Pouwer 2001	B	Unclear	Yes	Yes	400

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Piette 2000	B	No	Yes	Yes	280
Davies 2001	B	Unclear	Yes	Yes	300
New 2004	A	Yes	Unclear	No	5371
Piette 2001	A	Yes	Yes	Yes	292
New 2003	A	Yes	Unclear	Yes	1407
Taylor 2003	B	Yes	Yes	No	269
Wong 2005	C	Yes	No	Yes	101
Epilepsy					
Helde 2005	A	Yes	Yes	Yes	114
Ridsdale 1999	B	Unclear	Unclear	Yes	251
Health Promotion					
Chan 2005	B	Unclear	Not reported	Yes 56	
Roderick 1997	B	Unclear	Unclear	Yes	956
Taylor 1996	B	Unclear	Yes (excluded deaths)	Yes 660	
Bennett 2005	C	Unclear	Unclear	Yes	139
Becker 1998	B	Unclear	Yes	No	156
Ammerman 2003	B	Yes	Unclear	No	468
Hypertension					
Artinian 2001	A	Yes	No	Yes	26
Bosworth 2005	A	Unclear	Unclear	Yes	588
Rudd 2004	B	Yes	Unclear	Yes	150
Schroeder 2005	B	Yes (electronic)	Yes Yes		245
Not condition specific					
Johnston 2000	B	Unclear	Not reported	No 212	

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Mundinger 2000		B	Unclear	No	No	1316
Ogden Burke	1997	A	Unclear	Not reported	Yes 50	
Gagnon 1999		A	Yes	Yes	No	427
Other						
Yardley 2004		A	Yes	Yes	Yes	
Parkinson's						
Reynolds 2000		B	Unclear	Unclear	No	185
Jahanshahi 1994		B	Yes	Unclear	No	64
Hurwitz 1999		A	Unclear	Unclear	Yes	1836
Rheumatology						
Victor 2005		B	Yes	Unclear	No	193
Ryan 2006		A	Unclear	No	Yes	71
Blixen 2004		B	Yes	Not reported	Yes 32	
Tijhuis 2002/	03	A Yes		Yes	No	210
Hill 2003		B	Yes	Yes	Yes	80
Hill 1997		B	Unclear	Unclear	Yes	70
Stroke						
Boter 2004		A	Yes	Yes	Yes	536
Burton 2005		A	Yes	Yes	Yes	176
Ellis 2005		A	Yes	Yes	Yes	208
Forster 1996		A	Unclear	Yes	Yes	240
Larson 2005		B	Unclear	Unclear	Yes	100

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Appendix 20 Evidence Tables

See separate appendix document

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Appendix 21 Adolescent's Self-Efficacy Scale

For each question, put a tick (✓) in the box (□) that describes YOU the best.

1. I can find ways to stop my condition making me feel sad.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

2. I can find ways to stop my condition making me feel lonely.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

3. I can find ways to stop my condition making me feel annoyed or fed-up.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

4. I can manage my symptoms so that I can take pleasure from the things that I enjoy.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

5. I can control my condition at school.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

6. I can control my condition when I am doing school games or PE.

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□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

7. I can control my condition when I am with my friends.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

8. I can control my condition when I go out with my family.

□	□	□	□	□
not at all sure	a little sure	somewhat sure	quite sure	very sure

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Appendix 22 Tables showing data from the adult case study sites

Table A1. Smoking status of patients

	Current smoker status					
Site	**Smoker (%)**		**Non-Smoker (%)**		**Missing (%)**	
PCN1	1	(1.6%)	63	(98.4%)	0	(0.0%)
PCN2	10	(13.3%)	65	(86.7%)	0	(0.0%)
NS1	16	(15.8%)	84	(83.2%)	1	(1.0%)
CM1	6	(17.6%)	28	(82.4%)	0	(0.0%)
NS2	5	(6.8%)	68	(93.2%)	0	(0.0%)
Total	**38**	**(11.0%)**	**308**	**(88.8%)**	**1**	**(0.3%)**

	Ex-smoker status					
Site	**Ex-Smoker (%)**		**Non-Smoker (%)**		**Missing (%)**	
PCN1	29	(46.0%)	33	(52.4%)	1	(1.6%)
PCN2	45	(69.2%)	20	(30.8%)	0	(0.0%)
NS1	31	(36.9%)	45	(53.6%)	8	(9.5%)
CM1	21	(75.0%)	7	(25.0%)	0	(0.0%)
NS2	23	(33.8%)	36	(52.9%)	9	(13.2%)
Total	**149**	**(48.4%)**	**141**	**(45.8%)**	**18**	**(5.8%)**

Table A2. Current alcohol consumption for patients

Site	**Responses**	**Missing (%)**		**>0 unit per week (%)**		**Mean (sd)**		**Median**	**IQR**	
PCN1	57	7	(10.9%)	35	(61.4%)	5.8	(7.9)	4.0	0.0	7.5
PCN2	71	4	(5.3%)	44	(62.0%)	6.2	(10.2)	2.0	0.0	7
NS1	92	9	(8.9%)	60	(65.2%)	4.9	(7.7)	2.0	0.0	6.8
CM1	31	3	(8.8%)	15	(48.4%)	5.1	(8.3)	0.0	0.0	8
NS2	65	8	(11.0%)	39	(60.0%)	4.5	(7.2)	2.0	0.0	6
Total	**316**	**31**	**(8.9%)**	**193**	**(61.1%)**	**5.3**	**(8.3)**	**2.0**	**0**	**7.0**

Table A3. Body Mass index for patients

Site	**Responses**	**Missing (%)**		**Mean (sd)**		**Median**	**IQR**	
PCN1	57	7	(10.9%)	31.6	(6.1)	30.2	26.7	35.7
PCN2	62	13	(17.3%)	29.4	(6.1)	27.9	25.1	33.8
NS1	72	29	(28.7%)	26.8	(5.7)	25.4	22.5	29.9
CM1	27	7	(20.6%)	25.7	(4.7)	25.1	22.7	28.2

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NS2	62	11	(15.1%)	28.4	(6.1)	27.5	24.2	31.0
Total	**280**	**67**	**(19.3%)**	**28.6**	**(6.1)**	**27.6**	**24.3**	**31.8**

Table A4. Occupation of patients

Site	Professional (%)	Skilled non-manual (%)	Skilled Manual (%)	Non-skilled manual (%)	Unskilled (%)
PCN1	20 (31.3%)	8 (12.5%)	19 (29.7%)	5 (7.8%)	5 (7.8%)
PCN2	17 (22.7%)	16 (21.3%)	25 (33.3%)	7 (9.3%)	5 (6.7%)
NS1	27 (26.7%)	11 (10.9%)	11 (10.9%)	11 (10.9%)	8 (7.9%)
CM1	4 (11.8%)	4 (11.8%)	7 (20.6%)	7 (20.6%)	6 (17.6%)
NS2	30 (41.1%)	11 (15.1%)	13 (17.8%)	3 (4.1%)	7 (9.6%)
Total	**98 (28.2%)**	**50 (14.4%)**	**75 (21.6%)**	**33 (9.5%)**	**31 (8.9%)**

Site	Never Employed (%)	Unemployed (%)	Full Time Education (%)	Missing (%)	Total (%)
PCN1	2 (3.1%)	3 (4.7%)	- -	2 (3.1%)	64
PCN2	1 (1.3%)	2 (2.7%)	- -	2 (2.7%)	75
NS1	6 (5.9%)	17 (16.8%)	4 (4.0%)	6 (5.9%)	101
CM1	2 (5.9%)	- -	1 (2.9%)	3 (8.8%)	34
NS2	1 (1.4%)	6 (8.2%)	1 (1.4%)	1 (1.4%)	73
Total	**12 (3.5%)**	**28 (8.1%)**	**6 (1.7%)**	**14 (4.0%)**	**347**

Table A5. Ethnicity of patients

Site	White (%)	Mixed (%)	Asian (%)	Black (%)	Missing (%)	Total
PCN1	63 (98.4%)	- -	- -	- -	1 (1.6%)	64
PCN2	72 (96.0%)	1 (1.3%)	- -	- -	2 (2.7%)	75
NS1	99 (98.0%)	- -	1 (1.0%)	- -	1 (1.0%)	101
CM1	32 (94.1%)	- -	- -	- -	2 (5.9%)	34
NS2	61 (83.6%)	- -	11 (15.1%)	1 (1.4%)	- -	73
Total	**327 (94.2%)**	**1 (0.3%)**	**12 (3.5%)**	**1 (0.3%)**	**6 (1.7%)**	**347**

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Table A6. Self assessed general health of patients (1 – worst to 100 – best)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	60	4	(6.7%)	58.95	(28.30)	70.00	41.25	80.00
PCN2	67	8	(11.9%)	57.42	(25.62)	50.00	40.00	80.00
NS1	84	17	(16.8%)	65.92	(24.48)	71.00	50.00	80.00
CM1	27	7	(25.9%)	31.82	(25.23)	30.00	10.00	30.00
NS2	71	2	(2.8%)	64.00	(22.07)	70.00	50.00	80.00
Total	**302**	**38**	**(11.0%)**	**59.30**	**(26.53)**	**65.00**	**40.00**	**80.00**

Table A7. EQ-5D of patients

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	59	5	(7.8%)	0.597	(0.369)	0.691	0.186	0.883
PCN2	74	1	(1.3%)	0.618	(0.318)	0.656	0.569	0.812
NS1	93	8	(7.9%)	0.784	(0.218)	0.810	0.680	1.000
CM1	32	2	(5.9%)	0.252	(0.339)	0.189	-0.069	0.569
NS2	68	5	(6.8%)	0.760	(0.269)	0.796	0.690	1.000
Total	**326**	**21**	**(6.1%)**	**0.654**	**(0.332)**	**0.700**	**0.510**	**1.000**
HODaR	311	23	(6.9%)	0.630	(0.325)	0.690	0.510	0.840

Table A8. Number of prescribed tablets or medicines taken daily by patients

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	62	2	(3.1%)	5.44	(3.68)	5.00	2.75	8.00
PCN2	74	1	(1.3%)	6.65	(3.95)	6.00	4.00	9.00
NS1	93	8	(7.9%)	3.62	(2.98)	3.00	1.00	5.00
CM1	30	4	(11.8%)	8.90	(4.47)	8.00	5.00	12.00
NS2	73	0	(0.0%)	5.78	(3.68)	5.00	3.00	9.00
Total	**332**	**15**	**(4.3%)**	**5.59**	**(3.93)**	**5.00**	**2.00**	**8.00**

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Table A9. Amount of time that patients forget to take their medications

Site	All of the Time (%)		Most of the Time (%)		Some of the Time (%)		A Little of the Time (%)	
PCN1	2	(3.1%)	1	(1.6%)	7	(10.9%)	14	(21.9%)
PCN2	1	(1.3%)	-	-	6	(8.2%)	17	(22.7%)
NS1	2	(2.0%)	-	-	13	(12.9%)	26	(25.7%)
CM1	-	-	2	(5.9%)	1	(2.9%)	4	(11.8%)
NS2	2	(2.7%)	1	(1.4%)	5	(6.8%)	23	(31.5%)
Total	**7**	**(2.0%)**	**4**	**(1.2%)**	**32**	**(9.2%)**	**84**	**(24.2%)**

Site	None of the Time (%)		Missing		Total
PCN1	38	(59.4%)	2	(3.1%)	64
PCN2	49	(65.3%)	2	(2.7%)	75
NS1	54	(53.5%)	6	(5.9%)	101
CM1	24	(70.6%)	3	(8.8%)	34
NS2	41	(56.2%)	1	(1.4%)	73
Total	**206**	**(59.4%)**	**14**	**(4.0%)**	**347**

Table A10. Number of patients who feel they benefit from their medication

Site	All of the Time (%)		Most of the Time (%)		Some of the Time (%)		A Little of the Time (%)	
PCN1	24	(37.5%)	22	(34.4%)	9	(14.1%)	5	(7.8%)
PCN2	21	(28.0%)	30	(40.0%)	13	(17.3%)	5	(6.7%)
NS1	44	(43.6%)	32	(31.7%)	15	(14.9%)	2	(2.0%)
CM1	7	(20.6%)	14	(41.2%)	9	(26.5%)	1	(2.9%)
NS2	31	(42.5%)	26	(35.6%)	10	(13.7%)	2	(2.7%)
Total	**127**	**(36.6%)**	**124**	**(35.7%)**	**56**	**(16.1%)**	**15**	**(4.3%)**

Site	None of the Time (%)		Missing		Total
PCN1	2	(3.1%)	2	(3.1%)	64
PCN2	1	(1.3%)	5	(6.7%)	75
NS1	2	(2.0%)	6	(5.9%)	101
CM1	1	(2.9%)	2	(5.9%)	34
NS2	1	(1.4%)	3	(4.1%)	75
Total	**7**	**(2.0%)**	**18**	**(5.2%)**	**347**

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Table A11. Number of visits patients made to the GP within the last 6 weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	62	2	(3.1%)	0.92	(1.00)	1.00	0.00	1.00
PCN2	68	7	(9.3%)	0.88	(1.88)	0.00	0.00	1.00
NS1	91	10	(9.8%)	1.12	(1.53)	1.00	0.00	1.00
CM1	31	3	(8.8%)	0.90	(1.27)	1.00	0.00	1.00
NS2	72	1	(1.4%)	0.89	(0.97)	1.00	0.00	1.00
Total	**324**	**23**	**(6.6%)**	**0.96**	**(1.39)**	**1.00**	**0.00**	**1.00**
HODaR	288	46	(13.8%)	1.17	(1.12)	1.00	0.00	2.00

Table A12. Number of visits patients made to a practice nurse of health assistant in the last six weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	59	5	(7.8%)	0.97	(0.93)	1.00	0.00	2.00
PCN2	69	6	(8.0%)	0.62	(1.13)	0.00	0.00	1.00
NS1	90	11	(10.9%)	0.71	(1.02)	0.00	0.00	1.00
CM1	30	4	(11.8%)	1.70	(2.09)	0.50	0.00	3.25
NS2	69	4	(5.5%)	0.83	(1.94)	0.00	0.00	1.00
Total	**317**	**30**	**(8.6%)**	**0.86**	**(1.42)**	**0.00**	**0.00**	**1.00**
HODaR	273	61	(18.3%)	0.90	(1.58)	0.00	0.00	1.00

Table A13 Number of visits patients made to a NHS walk-in centre or calls made to NHS Direct in the last six weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	52	12	(18.8%)	0.02	(0.14)	0.00	0.00	0.00
PCN2	60	15	(20.0%)	0.05	(0.29)	0.00	0.00	0.00
NS1	82	19	(18.8%)	0.15	(0.50)	0.00	0.00	0.00
CM1	26	8	(23.5%)	0.12	(0.33)	0.00	0.00	0.00
NS2	67	6	(8.2%)	0.10	(0.35)	0.00	0.00	0.00
Total	**287**	**60**	**(17.3%)**	**0.09**	**(0.36)**	**0.00**	**0.00**	**0.00**
HODaR	250	84	(25.1%)	0.29	(1.13)	0.00	0.00	0.00

Table A14. Number of visits to patients made by any nurses in the last six weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	52	12	(18.8%)	0.29	(1.68)	0.00	0.00	0.00
PCN2	62	13	(17.3%)	0.63	(2.52)	0.00	0.00	0.00
NS1	84	17	(16.8%)	0.26	(1.44)	0.00	0.00	0.00
CM1	32	2	(5.9%)	4.44	(4.68)	3.00	2.00	4.75
NS2	69	4	(5.5%)	0.33	(1.63)	0.00	0.00	0.00
Total	**299**	**48**	**(13.8%)**	**0.81**	**(2.62)**	**0.00**	**0.00**	**0.00**

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HODaR	257	77	(23.1%)	0.68	(2.83)	0.00	0.00	0.00

Table A15. Number of visits to patients made by other health services staff in the last six weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	51	13	(20.3%)	0.18	(0.56)	0.00	0.00	0.00
PCN2	63	12	(16.0%)	0.14	(0.44)	0.00	0.00	0.00
NS1	84	17	(16.8%)	0.24	(1.26)	0.00	0.00	0.00
CM1	29	5	(14.7%)	1.34	(1.82)	1.00	0.00	2.00
NS2	67	6	(8.2%)	0.07	(0.32)	0.00	0.00	0.00
Total	**294**	**53**	**(15.3%)**	**0.28**	**(1.00)**	**0.00**	**0.00**	**0.00**
HODaR	256	78	(23.4%)	0.28	(1.33)	0.00	0.00	0.00

Table A16. Number of visits to patients made by social services in the last six weeks

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	51	13	(20.3%)	0.00	(0.00)	0.00	0.00	0.00
PCN2	61	14	(18.7%)	0.74	(5.38)	0.00	0.00	0.00
NS1	82	19	(18.8%)	0.82	(4.85)	0.00	0.00	0.00
CM1	28	6	(17.6%)	6.96	(18.95)	0.00	0.00	1.00
NS2	67	6	(8.2%)	0.02	(0.12)	0.00	0.00	0.00
Total	**289**	**58**	**(16.7%)**	**1.07**	**(7.08)**	**0.00**	**0.00**	**0.00**
HODaR	249	85	(25.4%)	0.53	(5.39)	0.00	0.00	0.00

Table A17. Number of days taken off paid employment in the last six weeks by patients

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	43	21	(32.8%)	1.19	(6.49)	0.00	0.00	0.00
PCN2	53	22	(29.3%)	3.17	(10.48)	0.00	0.00	0.00
NS1	71	30	(29.7%)	1.96	(5.63)	0.00	0.00	0.00
CM1	17	17	(50.0%)	0.00	(0.00)	0.00	0.00	0.00
NS2	57	16	(21.9%)	1.23	(5.89)	0.00	0.00	0.00
Total	**241**	**106**	**(30.5%)**	**1.78**	**(7.02)**	**0.00**	**0.00**	**0.00**
HODaR	218	116	(34.7%)	4.95	(11.85)	0.00	0.00	0.00

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Table A18. Number of days spent away from normal activities, other than paid employment, in the last six weeks by patients

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	50	14	(21.9%)	3.58	(7.70)	0.00	0.00	4.00
PCN2	62	13	(17.3%)	6.81	(12.95)	0.00	0.00	6.25
NS1	79	22	(21.8%)	3.30	(7.34)	0.00	0.00	5.00
CM1	21	13	(38.2%)	15.76	(19.77)	0.00	0.00	42.00
NS2	65	8	(11.0%)	3.52	(9.35)	0.00	0.00	0.00
Total	**277**	**70**	**(20.2%)**	**5.13**	**(11.07)**	**0.00**	**0.00**	**4.00**
HODaR	251	83	(24.9%)	9.18	(15.10)	0.00	0.00	14.00

Table A19. Number of days where care from friends or relatives has been needed in the last six weeks by patients

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	52	12	(18.8%)	6.23	(13.20)	0.00	0.00	4.75
PCN2	66	9	(12.0%)	8.05	(14.75)	0.00	0.00	10.00
NS1	84	17	(16.8%)	5.57	(11.88)	0.00	0.00	4.75
CM1	30	4	(11.8%)	31.13	(16.91)	42.00	17.75	42.00
NS2	66	7	(9.6%)	4.73	(12.32)	0.00	0.00	0.00
Total	**298**	**49**	**(14.1%)**	**8.62**	**(15.38)**	**0.00**	**0.00**	**7.00**
HODaR	256	78	(23.4%)	9.47	(14.92)	1.00	0.00	10.75

Table A20. Number of times patients have stayed overnight in hospital in the last six months (related to one of the patients' illnesses)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	50	14	(21.9%)	0.30	(1.52)	0.00	0.00	0.00
PCN2	61	14	(18.7%)	0.53	(1.99)	0.00	0.00	0.00
NS1	82	19	(18.8%)	0.26	(0.93)	0.00	0.00	0.00
CM1	28	6	(17.6%)	1.82	(4.55)	0.00	0.00	1.00
NS2	67	6	(8.2%)	1.15	(5.66)	0.00	0.00	0.00
Total	**288**	**59**	**(17.0%)**	**0.68**	**(3.32)**	**0.00**	**0.00**	**0.00**
HODaR	0	334	(100%)	-	-	-	-	-

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Table A21. Number of nights spent in hospital in the last six months by patients (related to one of the patients' illnesses)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	51	13	(20.3%)	0.216	(0.76)	0.00	0.00	0.00
PCN2	62	13	(17.3%)	1.81	(7.11)	0.00	0.00	0.00
NS1	83	18	(17.8%)	0.76	(2.78)	0.00	0.00	0.00
CM1	27	7	(20.6%)	2.52	(5.27)	0.00	0.00	3.00
NS2	68	5	(6.8%)	2.59	(8.57)	0.00	0.00	0.00
Total	**291**	**56**	**(16.1%)**	**1.48**	**(5.74)**	**0.00**	**0.00**	**0.00**
HODaR	0	334	(100%)	-	-	-	-	-

Table A22. Number of nights spent in hospital prior to the last six months by patients (related to one of the patients' illnesses)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	39	25	(39.1%)	11.36	(37.67)	0.00	0.00	4.00
PCN2	49	26	(34.7%)	3.41	(7.05)	0.00	0.00	4.00
NS1	61	40	(39.6%)	6.69	(32.62)	0.00	0.00	1.00
CM1	15	19	(55.9%)	2.87	(4.27)	0.00	0.00	5.00
NS2	47	26	(35.6%)	4.38	(22.06)	0.00	0.00	0.00
Total	**211**	**136**	**(39.2%)**	**6.01**	**(26.23)**	**0.00**	**0.00**	**1.00**
HODaR	0	334	(100%)	-	-	-	-	-

Table A23. Physical health score of patients measured with SF12

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	54	10	(15.6%)	42.76	(10.96)	44.67	35.86	52.14
PCN2	59	16	(21.3%)	39.17	(11.40)	40.31	28.73	47.67
NS1	85	16	(15.8%)	45.73	(14.05)	50.76	38.97	55.33
CM1	23	11	(32.4%)	22.17	(6.46)	20.05	17.40	27.14
NS2	66	7	(9.6%)	47.16	(11.53)	52.11	41.52	55.91
Total	**287**	**60**	**(17.3%)**	**42.26**	**(13.55)**	**44.96**	**33.84**	**54.20**
HODaR	32	302	(90.4%)	42.94	(12.69)	44.98	32.07	55.74

Table A24. Mental health score of patients measured with SF12

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	54	10	(15.6%)	50.97	(8.84)	53.74	47.81	57.21
PCN2	59	16	(21.3%)	49.69	(7.75)	50.61	44.91	55.92
NS1	85	16	(15.8%)	48.45	(7.35)	48.45	44.20	54.55
CM1	23	11	(32.4%)	44.86	(10.50)	46.73	41.36	51.32

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NS2	66	7	(9.6%)	49.66	(6.77)	51.64	45.26	55.25
Total	**287**	**60**	**(17.3%)**	**49.12**	**(7.99)**	**50.61**	**44.70**	**55.32**
HODaR	32	302	(90.4%)	43.21	(10.43)	45.04	38.99	48.88

Table A25. General health of patients

Site	Excellent (%)		Very Good (%)		Good (%)		Fair (%)	
PCN1	-	-	10	(15.6%)	23	(35.9%)	22	(34.9%)
PCN2	2	(2.7%)	8	(10.7%)	22	(29.3%)	32	(42.7%)
NS1	4	(4.0%)	15	(14.9%)	45	(44.6%)	32	(31.7%)
CM1	-	-	-	-	-	-	13	(38.2%)
NS2	2	(2.7%)	17	(23.3%)	19	(26.0%)	25	(34.2%)
Total	**8**	**(2.3%)**	**50**	**(14.4%)**	**109**	**(31.4%)**	**124**	**(35.7%)**

Site	Poor (%)		Missing (%)		Total
PCN1	8	(12.5%)	1	(1.6%)	64
PCN2	9	(12.0%)	2	(2.7%)	75
NS1	3	(3.0%)	2	(2.0%)	101
CM1	18	(52.9%)	3	(8.8.%)	34
NS2	10	(13.7%)	-	-	73
Total	**48**	**(13.8%)**	**8**	**(2.3%)**	**347**

Table A26. Are patients limited when conducting moderate activities due to their health?

Site	Yes, limited a lot (%)		Yes, limited a little (%)		No, not limited at all (%)		Missing (%)		Total
PCN1	14	(21.9%)	24	(37.5%)	26	(40.6%)	-	-	64
PCN2	24	(32.0%)	25	(33.3%)	21	(28.0%)	5	(6.7%)	75
NS1	11	(10.9%)	30	(29.7%)	56	(55.4%)	4	(4.0%)	101
CM1	30	(88.2%)	-	-	1	(2.9%)	3	(8.8%)	34
NS2	12	(16.4%)	15	(20.5%)	46	(63.0%)	-	-	73
Total	**91**	**(26.2%)**	**94**	**(27.1%)**	**150**	**(43.2%)**	**12**	**(3.5%)**	**347**

Table A27. Are patients limited when climbing stairs due to their health?

Site	Yes, limited a lot (%)		Yes, limited a little (%)		No, not limited at all (%)		Missing (%)		Total
PCN1	16	(25.0%)	23	(35.9%)	23	(35.9%)	2	(3.1%)	62
PCN2	33	(44.0%)	26	(34.7%)	12	(16.0%)	4	(5.3%)	75
NS1	14	(13.9%)	27	(26.7%)	54	(53.5%)	6	(5.9%)	101
CM1	28	(82.4%)	1	(2.9%)	-	-	5	(14.7%)	34
NS2	16	(21.9%)	17	(23.3%)	40	(54.8%)	-	-	73
Total	**107**	**(30.8%)**	**94**	**(27.1%)**	**129**	**(37.2%)**	**17**	**(4.9%)**	**347**

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Table A28. Have patients accomplished less in work or other regular daily activities during the past four weeks due to their physical health?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	11	(17.2%)	8	(12.5%)	17	(26.6%)	7	(10.9%)
PCN2	12	(16.0%)	14	(18.7%)	20	(26.7%)	9	(12.0%)
NS1	8	(7.9%)	11	(10.9%)	21	(20.8%)	15	(14.9%)
CM1	21	(61.8%)	6	(17.6%)	2	(5.9%)	1	(2.9%)
NS2	6	(8.2%)	7	(9.6%)	15	(20.5%)	14	(19.2%)
Total	**58**	**(16.7%)**	**46**	**(13.3%)**	**75**	**(21.6%)**	**46**	**(13.3%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	17	(26.6%)	4	(6.3%)	64
PCN2	16	(21.3%)	4	(5.3%)	75
NS1	41	(40.6%)	5	(5.0%)	101
CM1	1	(2.9%)	3	(8.8%)	34
NS2	30	(41.1%)	1	(1.4%)	73
Total	**105**	**(30.3)**	**17**	**(4.9%)**	**347**

Table A29. Were patients limited in the kind of work or other regular daily activities during the past four weeks due to their physical health?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	6	(9.4%)	11	(17.2%)	17	(26.6%)	6	9.4%)
PCN2	10	(13.3%)	12	(16.0%)	18	(24.0%)	6	(8.0%)
NS1	10	(9.9%)	6	(5.9%)	21	(20.8%)	15	(14.9%)
CM1	19	(55.9%)	7	(20.6%)	-	-	2	(5.9%)
NS2	7	(9.6%)	4	(5.5%)	11	(15.1%)	15	(20.5%)
Total	**52**	**(15.0%)**	**40**	**(11.5%)**	**67**	**(19.3%)**	**44**	**(12.7%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	20	(31.3%)	4	(6.3%)	64
PCN2	18	(24.0%)	11	(14.7%)	75
NS1	40	(39.6%)	9	(8.9%)	101
CM1	-	-	6	(17.6%)	34
NS2	32	(43.8%)	4	(5.5%)	73
Total	**110**	**(31.7%)**	**34**	**(9.8%)**	**347**

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Table A30. Have patients accomplished less in work or other regular daily activities during the past four weeks due to emotional problems?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	2	(3.1%)	8	(12.5%)	11	(17.2%)	7	(10.9%)
PCN2	3	(4.0%)	8	(10.7%)	23	(30.7%)	8	(10.7%)
NS1	3	(3.0%)	12	(11.9%)	21	(20.8%)	13	(12.9%)
CM1	9	(26.5%)	3	(8.8%)	3	(8.8%)	5	(14.7%)
NS2	3	(4.1%)	4	(5.5%)	10	(13.7%)	17	(23.3%)
Total	**20**	**(5.8%)**	**35**	**(10.1%)**	**68**	**(19.6%)**	**50**	**(14.4%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	32	(50.0%)	4	(6.3%)	64
PCN2	27	(36.0%)	6	(8.0%)	75
NS1	46	(45.5%)	6	(5.9%)	101
CM1	11	(32.4%)	3	(8.8%)	34
NS2	37	(50.7%)	2	(2.7%)	73
Total	**153**	**(44.1%)**	**21**	**(6.1%)**	**347**

Table A31. Did patients undertake work less carefully than usual during the past four weeks due to emotional problems?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	1	(1.6%)	5	(7.8%)	9	(14.1%)	9	(14.1%)
PCN2	3	(4.0%)	7	(9.3%)	22	(29.3%)	10	(13.3%)
NS1	2	(2.0%)	8	(7.9%)	23	(22.8%)	17	(16.8%)
CM1	6	(17.6%)	2	(5.9%)	2	(5.9%)	6	(17.6%)
NS2	3	(4.1%)	3	(4.1%)	7	(9.6%)	17	(23.3%)
Total	**15**	**(4.3%)**	**25**	**(7.2%)**	**63**	**(18.2%)**	**59**	**(17.0%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	34	(53.1%)	6	(9.4%)	64
PCN2	24	(32.0%)	9	(12.0%)	75
NS1	42	(41.6%)	9	(8.9%)	101
CM1	10	(29.4%)	8	(23.5%)	34
NS2	39	(53.4%)	4	(5.5%)	73
Total	**149**	**(42.9%)**	**36**	**(10.4%)**	**347**

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Table A32. Did patients find that pain interfered with normal work during the past four weeks?

Site	Not at all (%)		Slightly (%)		Moderately (%)		Quite a bit (%)	
PCN1	19	(29.7%)	12	(18.8%)	11	(17.2%)	14	(21.9%)
PCN2	17	(22.7%)	13	(17.3%)	15	(20.0%)	22	(29.3%)
NS1	54	(53.5%)	19	(18.8%)	12	(11.9%)	12	(11.9%)
CM1	5	(14.7%)	1	(2.9%)	1	(2.9%)	9	(26.5%)
NS2	40	(54.8%)	12	(16.4%)	3	(4.1%)	14	(19.2%)
Total	**135**	**(38.9%)**	**57**	**(16.4%)**	**42**	**(12.1%)**	**71**	**(20.5%)**

Site	Extremely (%)		Missing (%)		Total
PCN1	8	(12.5%)	-	-	64
PCN2	6	(8.0%)	2	(2.7%)	75
NS1	-	-	4	(4.0%)	101
CM1	18	(52.9%)	-	-	34
NS2	4	(5.5%)	-	-	73
Total	**36**	**(10.4%)**	**6**	**(1.7%)**	**347**

Table A33. How much of the time have patients felt calm and peaceful during the past four weeks?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	10	(15.6%)	28	(43.8%)	13	(20.3%)	8	(12.5%)
PCN2	4	(5.3%)	29	(38.7%)	28	(37.3%)	10	(13.3%)
NS1	11	(10.9%)	41	(40.6%)	32	(31.7%)	11	(10.9%)
CM1	3	(8.8%)	7	(20.6%)	8	(23.5%)	7	(20.6%)
NS2	5	(6.8%)	36	(49.3%)	19	(26.0%)	4	(5.5%)
Total	**33**	**(9.5%)**	**141**	**(40.6%)**	**100**	**(28.8%)**	**43**	**(12.4%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	5	(7.8%)	-	-	64
PCN2	3	(4.0%)	1	(1.3%)	75
NS1	4	(4.0%)	2	(2.0%)	101
CM1	6	(17.6%)	3	(8.8%)	34
NS2	7	(9.6%)	2	(2.7%)	73
Total	**22**	**(6.3%)**	**8**	**(2.3%)**	**347**

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Table A34. How much of the time did patients have a lot of energy during the past four weeks?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	1	(1.6%)	14	(21.9%)	17	(26.6%)	19	(29.7%)
PCN2	4	(5.3%)	13	(17.3%)	25	(33.3%)	14	(18.7%)
NS1	4	(4.0%)	29	(28.7%)	35	(34.7%)	20	(19.8%)
CM1	-	-	1	(2.9%)	1	(2.9%)	8	(23.5%)
NS2	4	(5.5%)	21	(28.8%)	25	(34.2%)	9	(12.3%)
Total	**13**	**(3.7%)**	**78**	**(22.5%)**	**103**	**(29.7%)**	**70**	**(20.2%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	13	(20.3%)	-	-	64
PCN2	17	(22.7%)	2	(2.7%)	75
NS1	9	(8.9%)	4	(4.0%)	101
CM1	19	(55.9%)	5	(14.7%)	34
NS2	12	(16.4%)	2	(2.7%)	73
Total	**70**	**(20.2%)**	**13**	**(3.7%)**	**347**

Table A35. How much of the time have patients felt downhearted and depressed during the past four weeks?

Site	All of the time (%)		Most of the time (%)		Some of the time (%)		A little of the time (%)	
PCN1	5	(7.8%)	6	(9.4%)	10	(15.6%)	13	(20.3%)
PCN2	2	(2.7%)	6	(8.0%)	22	(29.3%)	22	(29.3%)
NS1	2	(2.0%)	9	(8.9%)	29	(28.7%)	32	(31.7%)
CM1	3	(8.8%)	3	(8.8%)	14	(41.2%)	7	(20.6%)
NS2	1	(1.4%)	7	(9.6%)	17	(23.3%)	23	(31.5%)
Total	**13**	**(3.7%)**	**31**	**(8.9%)**	**92**	**(26.5%)**	**94**	**(28.0%)**

Site	None of the time (%)		Missing (%)		Total
PCN1	30	(46.9%)	-	-	64
PCN2	21	(28.0%)	2	(2.7%)	75
NS1	26	(25.7%)	3	(3.0%)	101
CM1	7	(20.6%)	-	-	34
NS2	23	(31.5%)	2	(2.7%)	73
Total	**107**	**(30.8%)**	**7**	**(2.0%)**	**347**

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Table A36. How much of the time has physical health or emotional problems interfered with social activities in patients during the past four weeks?

Site	All of the time (%)	Most of the time (%)	Some of the time (%)	A little of the time (%)
PCN1	5 (7.8%)	6 (9.4%)	12 (18.8%)	9 (14.1%)
PCN2	5 (6.7%)	8 (10.7%)	26 (34.7%)	13 (17.3%)
NS1	3 (3.0%)	9 (8.9%)	33 (32.7%)	16 (15.8%)
CM1	16 (47.1%)	11 (32.4%)	3 (8.8%)	1 (2.9%)
NS2	1 (1.4%)	6 (8.2%)	15 (20.5%)	14 (19.2%)
Total	**30 (8.6%)**	**40 (11.5%)**	**89 (25.6%)**	**53 (15.3%)**

Site	None of the time (%)	Missing (%)	Total
PCN1	32 (50.0%)	- -	64
PCN2	23 (30.7%)	- -	75
NS1	40 (39.6%)	- -	101
CM1	2 (5.9%)	1 (2.9%)	34
NS2	37 (50.7%)	- -	73
Total	**134 (38.6%)**	**1 (0.3%)**	**347**

Table A37. Confidence in the ability to keep fatigue from interfering with the things that patients wanted to do (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)	Mean (sd)	Median	IQR	
PCN1	62	2 (3.1%)	6.65 (2.64)	7.00	4.75	9.00
PCN2	72	3 (4.0%)	6.00 (2.63)	6.00	4.00	8.00
NS1	97	4 (4.0%)	6.75 (2.86)	8.00	5.00	9.00
CM1	34	0 (0.0%)	3.18 (2.28)	3.00	1.00	4.25
NS2	73	0 (0.0%)	7.16 (2.38)	8.00	5.00	9.00
Total	**338**	**9 (2.6%)**	**6.30 (2.83)**	**7.00**	**4.00**	**9.00**

Table A38. Confidence in the ability to keep physical pain from interfering with the things that patients wanted to do (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)	Mean (sd)	Median	IQR	
PCN1	63	1 (1.6%)	6.62 (2.86)	7.00	4.00	9.00
PCN2	73	2 (2.7%)	5.80 (2.80)	6.00	3.50	8.00
NS1	97	4 (4.0%)	7.22 (2.69)	8.00	5.00	10.00
CM1	34	0 (0.0%)	3.06 (2.35)	2.50	1.00	5.00
NS2	73	0 (0.0%)	7.59 (2.68)	9.00	5.00	10.00
Total	**340**	**7 (2.0%)**	**6.47 (3.00)**	**7.00**	**4.00**	**9.00**

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Table A39. Confidence in the ability to keep emotional distress from interfering with the things that patients wanted to do (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	63	1	(1.6%)	7.43	(2.81)	9.00	5.00	10.00
PCN2	72	3	(4.0%)	6.71	(2.56)	7.00	5.00	8.75
NS1	97	4	(4.0%)	6.87	(2.61)	8.00	5.00	9.00
CM1	34	0	(0.0%)	4.56	(3.00)	4.00	2.00	7.00
NS2	73	0	(0.0%)	7.70	(2.43)	8.00	5.00	10.00
Total	**339**	**8**	**(2.3%)**	**6.89**	**(2.77)**	**8.00**	**5.00**	**9.00**

Table A40. Confidence in the ability to keep any other symptoms or health problems from interfering with the things that patients wanted to do (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	64	0	(0.0%)	6.75	(2.71)	7.00	5.00	9.00
PCN2	74	1	(1.3%)	6.12	(2.45)	6.00	4.00	8.00
NS1	97	4	(4.0%)	6.65	(2.68)	8.00	5.00	9.00
CM1	33	1	(2.9%)	3.49	(2.44)	3.00	1.00	5.00
NS2	73	0	(0.0%)	7.06	(2.53)	8.00	5.00	9.00
Total	**341**	**6**	**(1.7%)**	**6.33**	**(2.75)**	**7.00**	**4.00**	**9.00**

Table A41. Confidence in the ability to do different tasks and activities needed to manage health conditions in patients (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	64	0	(0.0%)	7.22	(2.55)	8.00	5.00	10.00
PCN2	73	2	(2.7%)	6.69	(2.42)	7.00	5.00	8.00
NS1	98	3	(3.0%)	7.08	(2.64)	8.00	5.00	9.00
CM1	34	0	(0.0%)	3.44	(2.56)	3.00	1.00	5.00
NS2	73	0	(0.0%)	7.86	(2.33)	9.00	6.00	9.00
Total	**342**	**5**	**(1.4%)**	**6.83**	**(2.76)**	**7.00**	**5.00**	**9.00**

Table A42. Confidence in the ability to do things other than take medication to reduce the affect of illness on everyday life in patients (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	64	0	(0.0%)	7.02	(2.76)	7.00	5.00	10.00
PCN2	73	2	(2.7%)	5.96	(2.74)	6.00	4.00	8.00
NS1	97	4	(4.0%)	6.32	(3.03)	7.00	4.00	8.50
CM1	33	1	(2.9%)	3.27	(2.47)	3.00	1.00	4.50
NS2	73	0	(0.0%)	7.08	(2.64)	8.00	5.00	9.00
Total	**340**	**7**	**(2.0%)**	**6.24**	**(2.97)**	**7.00**	**4.00**	**9.00**

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Table A43. Average Self Efficacy score across 6-item scale in patients (1 – not confident to 10 – totally confident)

Site	Responses	Missing (%)		Mean (sd)		Median	IQR	
PCN1	64	0	(0.0%)	6.98	(2.51)	7.42	5.33	9.29
PCN2	74	1	(1.3%)	6.19	(2.33)	6.08	4.75	8.16
NS1	99	2	(2.0%)	6.81	(2.32)	7.16	5.33	8.33
CM1	34	0	(0.0%)	3.48	(2.13)	3.00	2.25	4.58
NS2	73	0	(0.0%)	7.41	(2.26)	8.50	5.75	9.25
Total	**344**	**3**	**(0.9%)**	**6.50**	**(2.55)**	**6.66**	**4.83**	**8.66**

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Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.