The process of planning, development and implementation of a General Practitioner with a Special Interest service in Primary Care Organisations in England and Wales: a comparative prospective case study

prepared by:

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Acknowledgements

Abbreviations and explanation of terms

Many of these explanations are based on, or reproduced with permission, from the NHS Jargon Buster: Version 2 (February 2008) updated online at http://www.impressresp.com

Abbreviation	Term in full	Explanation of term
BLF	British Lung Foundation	A UK charity working for everyone affected by lung disease.
	Breathe Easy Groups	Breathe Easy is the British Lung Foundation support group network. There are over 200 groups throughout the UK offering support and information to anyone affected by lung disease.
COPD	Chronic Obstructive Pulmonary Disease	
CRG	Clinical Reference Group	A disease-specific local advisory group which may include professionals, patients and managers.
DGH	District General Hospital	Hospital which provides secondary care services to a community.
DoH	Department of Health	The government department responsible for shaping the direction of health and social care services.
ENT	Ear Nose and Throat	
EPP	Expert Patients Programme	An NHS programme designed to spread generic self-care and self-management skills to a wide range of people with long-term conditions.
GMS	General Medical Services	One of the main types of GP contract that sets out the core range of services provided by family doctors (GPs) and their staff and a national tariff.
GP	General Practitioner	Family doctor. Patients in the UK access healthcare through the GP practice with whom they are registered.
GPIAG	General Practice Airways Group	An independent charity representing primary care health professionals interested in delivering the best standards of respiratory care.
GPwSI	General Practitioners with a Special Interest	Practising GPs with a special expertise in (respiratory medicine) whose role often includes in-service development as well as clinical care.
LINks	Local Involvement Networks	LINks are established for every local authority area and aim to gather information from local people about health and social services.
LTC	Long-term conditions	
	LTC pyramid	A pyramid with three levels of professional and self-care widely adopted as a model of service

		provision for people with long-term conditions. It is based on categorising care according to risk stratification.
NHS	National Health Service	The publicly funded healthcare system in England and Wales.
NICE	National Institute for Health and Clinical Excellence	An independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health.
	NICE Guidelines	Recommendations on the appropriate treatment and care of patients with specific diseases and conditions (e.g. COPD) within the NHS in England and Wales.
NPM	New Public Management	A term used to describe 'modernisation' of public services involving stronger managerial control and market-based forms of organisation.
NSF	National Service Framework	These NHS documents set national standards for the provision of care for a range of disease areas.
PBC	Practice-based commissioning	English GP practices are responsible for commissioning care for their practice's population. They are given indicative budgets, and encouraged to consider alternative ways of providing the services.
	PBC clusters, or groups, PBC GP lead	PBC is structured differently in different places. There may be individual practices, GP practice clusters who commission together, or there may be just one GP cluster to cover the whole area. There is usually a local GP lead for each PBC cluster.
PbR	Payment by Results	How secondary care providers in England are now paid. There is a national fixed tariff for emergency care, elective in-patients, day cases and outpatients bought by NHS commissioners. The important principle is that only work done and recorded using appropriate coding is paid for.
PCC	Primary Care Collaborative	A UK initiative to facilitate development in primary care. Phase 3 of this initiative includes a focus on chronic obstructive pulmonary disease.
PEC	Professional Executive Committee	These clinical committees of PCTs have, amongst other duties, responsibility for setting practice indicative budgets and to approve proposals for the use of efficiency savings by practices.
PCO	Primary Care Organisation	Freestanding statutory NHS bodies (Primary Care Trust in England; Local Health Boards in Wales) with responsibility for delivering healthcare and health improvements to their local areas. They commission or directly provide a range of community health services such as district nursing as part of their functions.
	Enhanced services	Services within the GMS contract that are not essential or additional. Their main role is to help

		PCOs reduce demand on secondary care by providing more local services responsive to local need and that also provide value for money.
QoF	Quality and Outcome Framework	Part of the revised GP contract to incentivise practices to provide systematic care for people with long term conditions.
	QoF exceptions	Patients who are on the disease register for a particular condition but are excepted from the practice's QoF statistics because they meet at least one of the statutory exception criteria e.g. review is not possible because of extreme frailty or non-attendance for review.
UK	United Kingdom	
US	United States	

Executive Summary

Background

Policy underpinning cost-effective reconfiguration of care for people with long-term conditions (LTCs) has promoted the evolution of an increasing number of specialist medical and nursing roles, including General Practitioners with a Special Interest (GPwSI). The parallel move to a market-based system and the strengthening of commissioning at the time of a merger of Primary Care Organisations (PCOs) has resulted in a context of unprecedented organisational change. Rhetoric demands that patients are at the centre of these changes.

Aims

Using respiratory disease as an exemplar of LTCs, we aimed to describe, understand and compare the processes of workforce change (specifically the role of GPwSIs) in a theoretically selected sample of PCOs, to explore the impact of change on patient experience, and to derive models of good practice in relation to workforce change.

About this study

Our study proceeded in four phases:

I.	We carried out semi-structured interviews during the first 6 months of 2006 with a representative of a nationwide purposive sample of 30 PCOs with varying approaches to developing respiratory services.

II.	Using an approach modelled on organisational process research, we conducted a comparative prospective case study in four PCOs during 2006 to 2007 selected to show variation in respiratory services workforce change. Each case study was constructed around a description of the planning process, both historically and as it unfolded over time, focusing on the way local service histories and organisational dynamics shaped the planning and implementation of services.

III.	We used illness diaries and serial telephone interviews to explore patients' understanding and knowledge of the service system and the way they use the system to manage their illness in the context of their overall life situation. The themes identified were further explored in focus groups.

IV.	We convened a national workshop in February 2008 with 30 participants selected to represent a range of perspectives on the key themes identified by the case studies. Feedback was provided on the issues raised by our findings and four multidisciplinary break-out groups were asked to focus on specific emerging themes.

Data analysis was iterative and continued throughout the four phases of the study, in order to develop a narrative description of the planning process in the case study PCOs, and enable a comparison between cases.

Key findings

The impact of change: For many PCOs, the barriers of financial deficit, organisational uncertainty, disengaged clinicians, and contradictory policies presented insurmountable barriers to the effective development of sustainable services.

The importance of teamwork: Although almost all PCOs were developing services for people with complex needs (principally in order to reduce admissions and thereby reduce costs), the presence of multidisciplinary teams integrating primary and secondary care clinicians with PCO management, was associated with breadth of service provision addressing the needs of patients at all levels of the LTC pyramid i.e. including those with mild, moderate and severe disease.

The significance of professional boundaries: Models and implementation of workforce reconfiguration are strongly influenced by the negotiation and contest among local clinicians and managers about expertise and interest. Negotiations were played out against a broader context of financial deficits and organisational change.

The impact of commissioning: Commissioning focused service planning on the cost-effectiveness of services, but could also destabilise service arrangements by disrupting relationships on which these arrangements rested. Service arrangements locked in formal contracts may prevent the flexibility and informality needed for effective LTC management.

The importance of personal relationships: Despite the intentions underpinning the development of a more formal and transparent commissioning system, personal relationships based on common professional interest, past work history, friendships and collegiality were a key resource in service development, particularly in the context of change and instability. Relationships connecting those adopting new specialist roles to centres of decision making and influence were important in establishing a professional role and associated territory.

Specialist roles beyond clinical function: New specialist roles, for example that of a GPwSI, involved more than adoption of new clinical specialist work. These roles are part of a changing workforce dynamic in a managerially driven and market-based NHS. GPwSIs adopted strategic roles to influence service development and promote GP interests in new contexts.

The need for broader training: In addition to specialist clinical training, GPwSIs highlighted the need to learn management and leadership skills, specifically to develop an understanding of the commissioning process, in order to enable them to fulfil a strategic role. Core training for PCO commissioners should include the skills to understand and harness local resources and broker relationships within local service networks.

The need for flexible access to services to support self-care: Patients valued flexible access and regular communication at the boundary between professional and self-care in order to feel comfortable managing their conditions.

The potential of harnessing patients' awareness: Patients were not only aware of changes that affect their experience of immediate care provision including changes in the availability and type of providers, but also showed awareness of and interest in what was happening at regional and national levels, though none were actively involved in service redesign.

Generalisability

Our conclusions are derived from data collected in four case study PCOs and 30 screening interviews and focused on respiratory disease as an exemplar of long-term conditions.   We provide detailed contextual descriptions of the case studies to enable readers to determine the applicability to their particular organisational and workforce situation.

Conclusions

Implications for policy makers, commissioners and healthcare professionals

Harnessing local skills and brokering productive relationships with and between healthcare professionals from both primary and secondary care in order to build effective and sustainable networks are a pre-requisite for the introduction of new ways of working to deliver integrated services for people with LTCs.

Policy makers should review the impact of organisational change and commissioning and contracting, together with the policy of contestability, on systems of care for people with LTCs. Mechanisms to ensure flexibility in cross-sectoral relationships need to be built into systems of commissioning.

Training for GPwSIs (and other clinicians operating in similar roles) and managers of commissioning services for the care of people with LTCs need to provide the breadth of people and management skills required to work strategically and effectively within networks.

Systems of care for people with LTCs (such as respiratory disease) need to ensure flexible access and movement between self-care and professional support. The increasing diversity of professional roles and tendency for commissioning to create services targeted at separate packages of care introduces complexity for both patients and clinicians. Simplification of systems, clear sign-posting and co-ordination of individual patient care from a key trusted professional are essential.

Patients need to be supported to enable their awareness of and interest in the changes in delivery of their care to be harnessed, enabling them to contribute meaningfully to decisions about service development.

Implications for researchers

Further research should focus on:

- Observing the longer-term impacts of the market-led NHS on workforce development, professional boundaries, staff morale and impact on quality of care

- Understanding how commissioners can nurture effective clinical networks and at what level in the NHS they should operate

- Evaluating flexible models of service delivery to support self-care

- Exploring ways of supporting patient involvement in designing and supporting implementation of new models of care.

The Report

1 Introduction

This study was formulated in response to the research brief WK B2: 'The planning, development and implementation of workforce change: the impact on health outcomes and patient experiences'. (National Co-ordinating Centre for NHS Service Delivery and Organisation, 2004) and took place during 2006 to 2007.

1.1 *The research brief*

The review of the research evidence on workforce issues revealed a significant gap in the examination of strategies and processes used in the planning, development and implementation of workforce changes. The objective of the workforce research programme is to examine the existing 'drivers' behind the development of skill mix changes, and to study the process of planning and implementing change, including an assessment of the use of evidence in this process.

1.1.1 Objectives of the research brief

Specific questions to be addressed in the research were:

- What processes are used to design and plan the development of new workforce arrangements?

- What are the key drivers behind the planning process?

- To what extent are plans based on the use of evidence? What type and quality of evidence is used to inform planning?

- How much time do healthcare staff spend on training for their new/developing roles?

- How effective is this training in addressing required competencies?

- To what extent do different methods of planning and/or training regimes make any difference to patient experiences and health outcomes?

- Can any mechanisms of best practice be identified in the planning, training and deployment of new staff?

1.2 *The study in relation to the brief*

Our study aimed to address the objectives of the brief through an in-depth examination of the planning and implementation of workforce change in a selected sample of English and Welsh Primary Care Organisations (PCOs). The study focuses on the emergence of General Practitioner with a Special

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Interest (GPwSI) services in the context of reconfiguration of services for people with long-term respiratory diseases.

1.2.1 Long-term diseases: an exemplar of diversity in models of service provision

In response to a range of policy initiatives (Department of Health, 2004c), new professional roles are emerging to deliver care for people with long-term conditions (LTCs). In addition to a number of novel nursing roles, these new roles include that of the GPwSI; a role that may contribute clinical leadership to local development (Gerada et al, 2002).

Despite being responsible for significant morbidity and representing a considerable burden on the health service (British Thoracic Society, 2006), respiratory disease has not yet been the focus of policy directives in contrast to, for example, diabetes or cardiovascular services which have been prioritised through National Service Frameworks (NSFs: NHS documents which set national standards for the provision of care for a range of disease areas) (Department of Health, 2008b).   Our study of respiratory services allowed us to observe general trends in workforce change in a disease area which is developing outside overt national policy and political pressures, and which potentially competes with other disease areas for resources and position on Primary Care Organisation (PCO: Freestanding statutory NHS bodies with responsibility for delivering healthcare and health improvements to their local areas) agendas.

1.2.2 Respiratory GPwSIs as an exemplar workforce change

GPwSIs represent an adoption of some specialist, traditionally secondary care roles by primary care physicians and, as such, are an important area of workforce change, hitherto little understood, as previous research has focused primarily on new nursing roles (Carr-Hill et al, 2004; Elliott et al, 2004). The emergence of this new medical role offered the opportunity to understand the position adopted by GPwSIs as generalists working within specialist services, and the attitudes of other stakeholders which could determine if, and how, the role evolved. Comparison with other specialist roles, specifically nursing roles, provided further opportunity to understand wider trends in workforce change. Few of the new roles, either medical or nursing, had formal processes defining specialist training needs and accreditation processes: for GPwSIs, this was due to be formalised during the course of the study offering insights into how new professions defined, accepted and used formal training needs and standards.

1.3 The report

The report is structured as follows:

Section 2: Introduction to the policy background, description and summary of current evidence for new professional roles and the importance of self-care, overview of the theoretical underpinning of our report.

Sections 3 and 4:   Aim, objectives and methods.

Sections 5, 6 and 8: Results of the three phases of the study (Screening interviews, Case studies and Patient perspective)   **Sections 7 and 9** present data from more than one phase related to specific issues (role and training of GPwSIs, professional perspectives on patient involvement).

Section 10: Summary of the findings, the limitations and strengths of the study, and a discussion the issues raised in relation to the study objectives. Finally conclusions are drawn.

Section 11: Overview of the discussions at the workshop. The positioning of this overview in the report reflects the contribution the workshop made to our study. We presented our data and conclusions to the participants and invited their comment a) to validate or challenge our findings and b) to assist with formulation of the broader implications.

Section 12: Implications for policy-makers, commissioners, healthcare professionals and the research agenda.

2 Background

2.1 Summary

The increasing challenge of long-term conditions

Policy is driving a shift in the care for people with LTCs from the acute sector into the community.

Long-term respiratory conditions exemplify diseases that despite their significant burden have not been prioritised by central policy, although an NSF for COPD is now being developed and is due to be published in 2008.

Specialist services are being redesigned to meet the challenge

Of particular relevance to reconfiguration of the healthcare workforce is the integration of clinical care (for example through a care pathway) in a collaboration underpinned by shared values.

Specialists have responsibility for improving the quality of care at all levels of the pyramid of care for people with long-term conditions (LTC pyramid), by fulfilling strategic and educational roles, i.e. their role needs to extend beyond provision of clinical services for the minority of patients with complex needs.

New roles are emerging to meet the challenge

New roles and new ways of working (including GPwSIs, community matrons, and community-based specialist respiratory nurses) are emerging.

Existing research provides some evidence on single roles, (e.g. GPwSI, or specialist nurses), but little is known about how these new roles integrate within a local healthcare economy as services are reconfigured.

GPwSIs, originally intended to provide a clinical role within a narrowly defined specialty, have adopted a broader remit – including strategic, educational and clinical roles – in the provision of care for people with LTCs.

Patients as partners in meeting the challenge

Self-care is promoted both in recognition of patients' pivotal role in the care of their condition, and to enable healthcare services to meet the increasing challenge of providing care for people with LTCs.

Patients should be consulted about and actively contribute to decisions about reconfiguration of services to ensure that care is designed to meet their needs.

Understanding workforce change: Relevant literature

Innovations in healthcare organisations: Implementation of innovations in complex organisations is non-linear and is subject to a range of variables which interact with each other. Local context is highly influential.

The sociology of professional boundaries: Workforce change is a political process with professions and occupational groups negotiating and contesting territories of clinical work.

Increased managerialism or 'New Public Management': A central part of the NHS modernisation agenda is a strengthening of managerial functions, coupled with increased reliance on market mechanisms, to ensure strategic development towards cost-effective service arrangements.

Relationships in a market-based economy: Market reforms based on principles of commissioning structure relationships between healthcare professionals in new ways, and potentially alter the conditions of boundary work.

2.2 Long term conditions policy in the NHS

Health services globally are changing to meet the increasing challenge of providing care for people with LTCs in an ageing population (Department of Health, 2004c; World Health Organisation, 2002). In the UK, a consistent priority for NHS reform over the last decade has been the shift from provision of hospital-based acute care to care delivered in the community (Department of Health, 2000b; Department of Health, 2004f; Department of Health, 2006a). Primary care services, linked with community-based facilities, are evolving to provide integrated, patient-centred care delivered by *"...professionals with the right training in the right place"* (Department of Health, 2005b; Department of Health, 2006a; Department of Health, 2007c).

The LTC pyramid model of healthcare (see Figure 1) defines the needs of people with long-term diseases at three levels: i) supported self-management which encourages low-risk patients to take an active role in managing their own care; ii) disease management when multidisciplinary teams provide high-quality, evidence-based care to those at greater risk; and iii) case management involving the active management of high-risk people with complex needs (Department of Health, 2004c).

A wide range of initiatives are being introduced to provide care tailored to the needs of patients with these different levels of need (Department of Health, 2005c; Scottish Executive, 2005; The Strategy Unit, 2005). The Expert Patient initiative encourages self-management (Department of Health, 2001b), the General Medical Services (GMS) contract, (one of the main types of GP contract that sets out the core range of services provided by family doctors and their staff), is seen as a key enabler in improving chronic disease management in primary care (NHS confederation and British Medical Association, 2000), the Improvement Foundation (previously Primary Care Collaborative) is focusing on developing services for diabetes and chronic obstructive pulmonary disease (COPD) (National Primary Care Development Trust, 2008), and a number of different models of case-management are currently being piloted (NHS Modernisation Agency, 2004), some demonstrating benefits of formal liaison between generalists and specialists (Mitchell et al, 2002). Schemes with more specific remits, such as Hospital at Home and Early Supported Discharge are also being developed (Ram et al, 2004). The importance of clinical leadership, including GPwSIs, in contributing to this development agenda, is emphasised (Department of Health, 2007c; Department of Health, 2007e; NHS Alliance, 2006; NHS confederation and British Medical Association, 2000; Royal College of Physicians of London et al, 2004).

Figure 1. Pyramid of care for long-term conditions
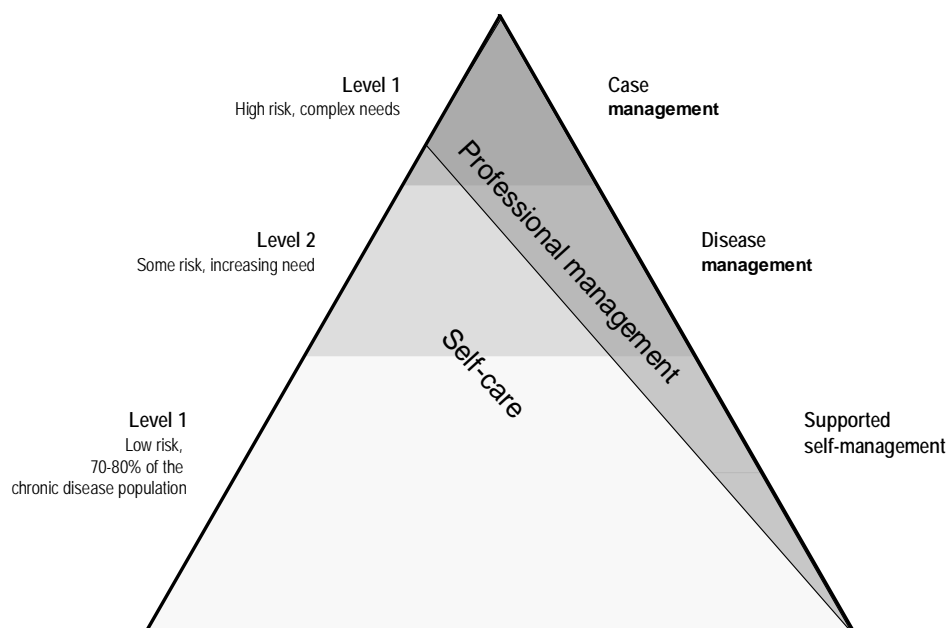
Although it is people with complex needs who are at most risk of hospital admission there is debate about whether resources should be targeted at those currently at the top of the pyramid, where the potential to reduce admissions may be limited as the condition may already be too severe for effective intervention (Curry et al, 2005). An alternative strategy might be to target those at the two lower levels, whose risk is likely to increase. In addition, individual risk profiles change over time, so that patients move between these levels of care. To address these issues, algorithms, including data on cost, utilisation of health services, diagnosis, use of drugs and demography, have been developed to provide predictive models, enabling those likely to be at highest risk to be identified and targeted for a case management approach (Cousins et al, 2002; Curry et al, 2005).

2.2.1 Respiratory disease as an exemplar of a long-term condition

Our study used reconfiguration of respiratory disease as an exemplar of the workforce change accompanying a shift of care from secondary care to community-based services. About 6% of adults in the UK report long-term respiratory illness (British Thoracic Society, 2006), making this the third commonest cause of long-term ill-health. There are over 5 million people with asthma in the UK, and over 80,000 admissions for acute asthma, an estimated 75% of which might have been prevented (National Asthma Panel, 2006). Respiratory disease is responsible for 1 in 5 deaths, which is more than ischaemic heart disease, and greater than in most other European countries (British Thoracic Society, 2006). COPD is responsible for a quarter of these deaths, 1.4 million GP consultations, a million hospital bed days, is the major contributory factor in the winter bed crises (Damiani

and Dixon, 2002) and costs the NHS over £800million each year (Department of Health, 2004d).   The socio-economic impact is considerable, as both patients and their carers lose time from work, estimated to cost the UK economy nearly £3 billion (The Respiratory Alliance, 2003).

Despite this burden of disease, respiratory conditions have not been considered a priority in the UK and have had to compete for resources with disease areas such as coronary heart disease and diabetes supported by the profile, structure and imperatives of NSFs. However, following two high profile reports which highlighted the need for personalised, structured and integrated care for people with COPD, in order to manage the disease burden more effectively (Commission for Healthcare Audit and Inspection, 2006; Department of Health, 2004d), an NSF has been commissioned (Department of Health, 2008b). The recent publication of the National Clinical Guideline for the Management of Chronic Obstructive Pulmonary Disease (National Institute for Clinical Excellence, 2004) and the incorporation of respiratory targets in the Quality and Outcome Framework (QOF: Part of the revised GP contract to incentivise practices to provide systematic care for people with long-term conditions) of the GMS Contract, have provided further impetus to this initiative (NHS confederation and British Medical Association, 2000). The restructuring of respiratory care thus gained momentum from national policy initiatives during our study.

2.3 Meeting the challenge of long term conditions: redesign of integrated specialist services

It is clear that the policy on workforce reconfiguration in relation to the shift of care for LTCs, implies far reaching organisational change (e.g. (Department of Health, 2000a; Department of Health, 2005b; Department of Health, 2007b). Two key considerations are integration of care and the functions of a specialist service.

2.3.1 Integration of care

Reconfiguration of specialist care involves integration of services and bridging divides between sectors, particularly between hospital and primary care and breaking down professional barriers to provide flexible and patient-centred care (Department of Health 2004b).   Three main potential routes to achieving vertical integration of care have been suggested (Fulop et al, 2007):

- Hospitals expanding outwards and downwards

- Primary care expanding outwards and upwards

- Formation of new organisations.

Integration may operate at many levels, including formal mergers or administrative integration, but of particular relevance to reconfiguration of the healthcare workforce, is integration of clinical care (for example through a care pathway) in a collaboration underpinned by shared values (Fulop et

al, 2007). Formal and informal clinical networks have an important role in determining success, or otherwise of organisational integration, leading to advice on the pivotal importance of direct conversations with clinicians, about changing the way the organisation delivers care (Fulop et al, 2007).

In a widely cited comparison with the integration achieved by the US-managed care organisation, Kaiser-Permanente, Light et al emphasise the importance of clinical dialogue concluding that "*doctors from primary, secondary and tertiary care should be given joint responsibility for managing clinical services*" (Light and Dixon, 2004).

2.3.2 Functions of a specialist service

In a recent discussion paper, Gask echoes this sentiment when she suggests that specialists should be actively involved in organisational change beyond the provision of clinical care. Gask concludes that specialists have responsibility for improving the quality of care at all levels of the LTC pyramid, not only providing clinical services for the minority of patients with complex needs (Gask, 2005).

Important functions of the specialist role, therefore, should include:

1. Clinical: Providing specialist clinical care for patients with complex needs.

2. Educational: Ensuring patients with lower level needs receive a quality service by setting and auditing standards, and providing education, training and support for primary care clinicians.

3. Strategic: Contributing clinical leadership by supporting the strategic development of a comprehensive and coherent local service.

Gask builds her argument on the consultant role in US-managed care organisations. Reconfiguration, however, is resulting in an increasingly diverse specialist workforce (GPwSI, community matrons, specialist respiratory nurses), which raises the question about whether clinicians in these new roles can fulfil all the functions of a specialist service, and whether services specifically commissioned to provide a clinical service will have the remit or resources to address educational and strategic functions.

2.4 Meeting the challenge of long-term conditions: new specialist roles

The policy of shifting care for people with LTCs into the community (Department of Health, 2005b; Department of Health, 2005c) has been accompanied by the emergence of healthcare professionals, such as GPwSIs, community-based consultants, specialist nurses and community matrons, who are developing skills to meet the need for specialist care in primary care settings (Royal College of Physicians of London et al, 2004; Sibbald et al, 2004; Williams et al, 2002). In the following section we describe the evolution of these roles, and the evidence-base relating to their effectiveness.

2.4.1 General Practitioners with a Special Interest

Evolution of the role

Publication of The NHS Plan signalled the creation of GPwSIs as a key component of the modernisation agenda (Department of Health, 2000b). The primary political motive for the role of GPwSIs was the imperative to reduce waiting lists for specialist opinions in areas such as ophthalmology, orthopaedics, dermatology and ear nose and throat surgery (ENT) and for specific procedures such as endoscopy (Department of Health, 2000b; Department of Health, 2002a). In discussion with the Department of Health and the Royal College of Physicians, the Royal College of General Practitioners has defined key concepts underpinning the role of GPwSIs (Department of Health, 2002a; Royal College of General Practitioners, 2001; Royal College of General Practitioners and Royal College of Physicians of London, 2001). These emphasise the importance of maintaining a primary care perspective while encouraging the cost-effective development of defined specialist competencies to meet local healthcare needs. Primary care interest societies, recognising the potential for developing care, have further delineated roles in a wider range of clinical areas (including respiratory) and involving a more strategic role in PCOs than was originally envisaged (Gerada et al, 2002; Williams et al, 2002).

In a discussion paper (Williams et al, 2002), the General Practice Airways Group (GPIAG: an independent charity representing primary care health professionals interested in delivering the best standards of respiratory care) recommended a number of potential roles for a respiratory GPwSI including:

- Leading the strategic planning within a PCO from a primary care perspective.

- Setting quality standards for respiratory care.

- Providing clinical expertise for conditions most common in general practice (e.g. asthma, COPD, and respiratory infections).

These concepts have been embodied in a guideline for respiratory GPwSIs (Department of Health, 2003a). The potential of GPwSIs to provide a strategic lead and act as an educator of other healthcare professional colleagues as well as offer a clinical service is emphasised in generic and respiratory-focused resources available to support PCOs (General Practice Airways Group, 2005; National Primary Care Development Trust, 2003).

Training and accreditation for the GPwSI role

In the early documentation training and accreditation were devolved to PCOs (National Primary Care Development Trust, 2003). The GPIAG led discussions that produced a number of advisory documents for respiratory GPwSIs, which emphasised the importance of generic skills, as well as disease-specific training (General Practice Airways Group and Royal College of General Practitioners, 2003; Gruffydd-Jones, 2005; Holmes and Gruffydd-Jones, 2005), but there was concern that the lack of official

guidance resulted in a lack of consistent standards in different PCOs (Coombe and Pitts, 2006).

Responding to that need, the Department of Health has now published guidance which states that GPwSIs are appointed to deliver a particular specialist clinical service within a defined integrated care pathway, and that clarity about the nature of that service is an essential precondition for successful accreditation (Department of Health, 2007a). The process, to be overseen by a local panel, is therefore one of accrediting a service, then accrediting the GPwSI to provide that service. Evidence of appropriate skills may be by a portfolio of relevant experience (Gruffydd-Jones, 2005), or through formal training (Bradford and Airedale Teaching PCT, ; Education for Health, 2008). The accreditation process focuses on fulfilling governance requirements for safe clinical practice, although it acknowledges the possibility of additional educational and strategic roles (Department of Health, 2007a).

The role of the GPwSI

A randomised controlled trial of a dermatology GPwSI service (Salisbury et al, 2005) and a number of observational studies have been published exploring the role of GPwSIs in: dermatology (Rosen et al, 2005); ENT (Sanderson, 2002); orthopaedics (Baker et al, 2005) and musculoskeletal services (Hay and Adebajo, 2005). Reflecting the findings of surveys (Pinnock et al, 2005), there are also descriptions of GPwSIs providing a range of services for: medical conditions (e.g. headaches (Kernick, 2005), diabetes and cardiology (Hill and Rutter, 2001), and attention deficit disorder (Salmon and Kirby, 2007)), surgical specialties (e.g. gynaecology (Hill and Rutter, 2001) and hernia repair (Dhumale, 2004)) and specific procedures (e.g. endoscopy (Galloway et al, 2002) and cystoscopy (Hill and Rutter, 2001)). Respiratory GPwSIs have been described in the context of seeing GP referrals (Gilbert et al, 2005) and leading community pulmonary rehabilitation services (Jones et al, 2002); (Ward et al, 2002).

The GPwSI role, as reported in the literature, demonstrates the diversity and fluidity of an evolving role. Some GPwSIs offer a procedural-based service (e.g. endoscopy), others provide an alternative source of expert opinion (e.g. dermatology service), while in some situations GPwSIs are a means of providing a new service (e.g. pulmonary rehabilitation). Anecdotally, some GPwSIs were focusing on the strategic and educational components of a specialist service, rather than providing a clinical service (General Practice Airways Group, 2005). Staffing levels, patient groups targeted, case loads and referral patterns were consequently equally varied.

Evidence-base for the GPwSI role

Referral patterns

There is consistent evidence that GPwSIs can safely provide care for a proportion of patients who would otherwise be referred to secondary care: e.g. 30-40% of patients referred to 1 of 6 ENT clinics (Sanderson, 2002) and 49% of patients referred to a dermatology clinic (Salisbury et al, 2005).

It has been estimated that between 23% and 57% of respiratory referrals are suitable for GPwSI care, especially those with COPD (Gilbert et al, 2005). Against this, some patients (12% of dermatology referrals (Salisbury et al, 2005), 25-20% of ENT referrals (Sanderson, 2002), 10% of headache referrals (Kernick, 2005)) are subsequently referred to a consultant, and in addition a new service may attract additional referrals, once it is established (Kernick, 2005; Sanderson, 2002). A study of three dermatology GPwSI services and one musculoskeletal clinic demonstrated an increase in overall referrals (Rosen et al, 2005).

Cost effectiveness

Studies of cost-effectiveness have shown diverse results, reflecting the importance of context. The randomised controlled trial of dermatology referrals concluded that GPwSI referrals cost £208 compared with £118 for a secondary care consultation, mainly because patients attending hospital outpatients might be seen by a (cheaper) registrar or clinical assistant (Roland et al, 2006). By contrast, ENT GPwSI consultations were only £30-£40, half the cost in secondary care (Sanderson, 2002). Similarly GPwSI-led community-based pulmonary rehabilitation, hernia repairs and headache consultations were half the cost of hospital care (Dhumale, 2004; Jones et al, 2002; Kernick, 2005).

Clinical outcomes and patient preferences

Reassuringly, clinical outcomes are similar (Baker et al, 2005; Roland et al, 2006; Salisbury et al, 2005), and patients are generally equally or more satisfied with the GPwSI service, often citing the relaxed atmosphere and convenient access offered by local clinics (Baker et al, 2005; Jones et al, 2002; Rosen et al, 2005; Salisbury et al, 2005; Sanderson, 2002). By contrast, a discrete choice experiment, to determine the preferences of participants of the dermatology GPwSI trial, concluded that thoroughness of care and the doctor's expertise were more important than the logistical issues such as convenient access and short waiting times (Coast et al, 2006).

Qualitative research has echoed the satisfaction surveys describing 'almost unanimous' praise and support expressed by patients for GPwSI services (Sanderson, 2002). GPwSIs furthermore enjoyed the challenge of developing their skills and thought that the diversity could prevent burn out and, in general, their practices were supportive. Primary care colleagues were broadly satisfied with the GPwSI service, though the additional clinic could cause confusion about appropriate referrals (Rosen et al, 2005). The relationships between the GPwSI, PCO staff and hospital specialists are a key determinant of the acceptability of the service (Rosen et al, 2005), with attitudes varying from good and supporting as both GPwSIs and their mentor consultant colleagues enjoyed working together (Rosen et al, 2005; Sanderson, 2002), to outright hostility and resistance (Rosen et al, 2005).

Requirements for the successful development of a GPwSI service.

Experience from pilot work has suggested that for a GPwSI service to be developed successfully the scheme must: align with local strategy

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(Sanderson, 2002); develop co-operation (including an arrangement for mentoring) between primary and secondary care (Rosen et al, 2005; Sanderson, 2002); involve a manager with vision and drive who is able to secure adequate, on-going funding (Sanderson, 2002); and recruit a GP interested in developing their professional skills (Sanderson, 2002). Similar recommendations were made by pilot areas in the broader context of implementing a range of service models to achieve 'care closer to home' (Department of Health, 2007d).

2.4.2 Community respiratory consultants

Specialist outreach clinics (consultant clinics run in a primary care setting) were a popular innovation of general practice fundholding (Shapiro and Perrett, 1998). As fundholding was disbanded amidst concerns about inequity of care provision, two systematic reviews considered the advantages and disadvantages of outreach clinics, in order to inform PCOs taking over responsibility for commissioning care (Gruen et al, 2003; Powell, 2002). UK-based surveys and qualitative studies suggested that, although outreach clinics were appreciated by patients for their convenience and offered opportunities for improved GP–specialist communication, they were generally expensive in terms of consultant time and costs (Powell, 2002). Similarly, a Cochrane review of international intervention studies showed that simply exchanging the hospital outpatients for a primary care clinic improved access, but had no effect on health outcomes (Gruen et al, 2003). However, outreach services that included collaboration with primary care or educational interventions facilitated implementation of guidelines and improved health outcomes, especially in rural and disadvantaged communities (Gruen et al, 2003). Commentators concluded that although outreach clinics were unlikely to replace outpatient clinics in their original format, the policy for 'community resource and treatment centres' (Department of Health, 2000b) would promote specialist care provided from well equipped 'polyclinics' and prompted speculation that in time PCOs would employ their own consultant staff (Gillam, 2001). 'Care closer to home' remains a central plank of Department of Health policy (Department of Health, 2006a; Department of Health, 2007c) and 'consultants in integrated respiratory care' working in the community (some employed by PCOs) are now a reality in respiratory medicine (IMPRESS, 2008). It has been suggested that the concept should be extended in the form of community medical centres run by partnerships of primary and secondary care physicians offering a 'hybrid' service (Black, 2006).

2.4.3 Specialist nurses

A key tenet of many of the recent NHS changes has been to extend and enhance nursing roles (Department of Health, 1999), to encompass some work traditionally done by GPs, and to enable people who are currently seen in hospital settings, to be cared for in the community (Department of Health, 2002b). Many such roles have been shown to be effective (Horrocks et al, 2002; Ram et al, 2003). Pilot work implementing 'care closer to home' included enhanced roles for nurses in ENT, gynaecology,

orthopaedics, dermatology, urology and general surgery (Department of Health, 2007d). Early examples of Nurses with a Special Interest cited respiratory care as a clinical area where nurses could potentially prevent admissions, provide pulmonary rehabilitation and advise GP and nurse colleagues in primary care (Department of Health, 2002b).

Respiratory nurses in management of acute COPD

A Cochrane review concluded that 1 in 4 carefully selected patients presenting to hospital emergency departments with acute exacerbations of COPD could be safely and successfully treated at home with support from respiratory nurses (Ram et al, 2003). Such 'hospital at home' services, whether preventing admissions or enabling early discharge, are now endorsed by national guidelines (British Thoracic Society, 2007; National Institute for Clinical Excellence, 2004).

These services typically involve hospital-based respiratory specialist nurses working as part of a specialist team, assessing patients presenting as a possible admission with an acute exacerbation of COPD. Patients, whose clinical and social situations do not require admission, are admitted to the Hospital at Home service until the exacerbation has resolved. Such services are widely promoted (Department of Health, 2002b; National Institute for Clinical Excellence, 2004).

Respiratory nurses in chronic disease management of COPD

By contrast, despite more than two decades of nurse-led respiratory care (Cockcroft et al, 1987; Littlejohns et al, 1991; Smith et al, 1999), the evidence, that nurse-led chronic disease management of people with COPD in the community improves morbidity or can reduce admissions, remains equivocal (Taylor et al, 2005). A trial, that demonstrated a reduction in readmission rates in patients on long-term oxygen therapy, showed that such care was cost-effective, despite five home visits and a hospital visit per patient in the intervention group (Farrero et al, 2001). Other trials, however, have shown no benefit (Bergner et al, 1988; Egan et al, 2002; Littlejohns et al, 1991; Smith et al, 1999; Smith et al, 2002). More recent trials have included self-management education programmes and the provision of emergency treatment packs, but have similarly shown contradictory results (Bourbeau et al, 2003; Monninkhof et al, 2003), limiting the overall conclusions that can be drawn (Effing et al, 2007).

A common feature of the nurse-led interventions is the active management of patients with complex needs, a 'case management' role which mirrors that of community matrons (Taylor et al, 2005). The patient groups targeted were therefore those with more severe disease. Most interventions included a strong emphasis on education and promoting self-care and almost all involved home visits by the nurse. Some of the interventions were short-term (e.g. for one month after an admission (Egan et al, 2002; Hermiz et al, 2003)) whilst other provided on-going care (e.g. up to a year (Bergner et al, 1988; Littlejohns et al, 1991; Smith et al, 1999)).

2.4.4 Community matrons

Community matrons were launched in 2005 to address the care of people with complex needs at the top of the Kaiser-Permanente pyramid (Department of Health, 2005c). Their role is to provide case management for high users of healthcare services, especially of costly inpatient care (Department of Health, 2005e), with each nurse being responsible for a case load of about 50 patients. Whilst there is evidence from qualitative studies that community matrons provide important psychosocial support to patients and their carers (Sargent et al, 2007), pilot studies of case management have not shown a reduction in hospital admissions (Gravelle et al, 2007). Whilst this may be due to poor identification of at-risk patients, there are concerns that this reflects previous evidence of limited effectiveness of case management (Hutt et al, 2004).

2.5 Meeting the challenge of long-term conditions: patients as partners in their care

The challenge of providing care for people with LTCs, and acknowledgement that the patient lives with and knows how their condition affects them better than any professional, has led to an increasing emphasis on the importance of the patient as a partner in their own care (Department of Health, 2004c; Department of Health, 2004f; Department of Health, 2006a). Two key strands of this agenda are the promotion of self-care to *"enable people with long-term conditions to take more control of their health"* and involvement of patient and public to give them *"more voice in how services are planned and provided*" (Department of Health, 2004f).

2.5.1 Patient involvement in self-care

The Expert Patient Programme (EPP), has been the subject of increasing investment (Department of Health, 2004f; Department of Health, 2006a), attempting to empower individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively (Department of Health, 2004b; Department of Health, 2004c; Department of Health, 2005c), and enabling informed choice at an individual level (Department of Health, 2006a). The aim is that patients will increasingly work in partnership with professionals, with the support of decision aids and information sharing, supported by the NHS Connecting for Health's National Programme for Information Technology (Department of Health, 2004f; Department of Health, 2005b).

There is evidence that, at least in some contexts, self-management training can improve outcomes (Bodenheimer et al, 2002; Coulter and Ellins, 2007) though a review of the impact of lay-led programmes in the UK concluded that although patient confidence improved, use of healthcare resources was not reduced (Griffiths et al, 2007). Qualitative research has identified factors influencing patients' acceptance of self-care strategies, including individual preference for autonomy which may be influenced by friends or family, perceived severity of physical symptoms, the impact of social

context, the timing in the course of the illness and adequacy of communication with their physician (Chapple and Rogers, 1999). The need to improve health literacy is fundamental (Coulter and Ellins, 2007; Sihota and Lennard, 2004).

In the context of respiratory disease, guided self-management is a key recommendation of national and international asthma guidelines (British Thoracic Society and Scottish Intercollegiate Guideline Network, 2003; The Global Initiative on Asthma, 2007) reflecting evidence of the effectiveness of regular reviews combined with self-management programmes in improving asthma morbidity (Gibson et al, 2002; Powell and Gibson, 2002). Despite recognition of the importance of helping people with COPD to self-manage their condition (Commission for Healthcare Audit and Inspection, 2006), current strategies for providing self-management education are inconclusive, with some evidence that written action plans can increase recognition and treatment (Turnock et al, 2005) but limited evidence of improvements in morbidity or use of healthcare resources (Monninkhof et al, 2003).

Whilst generally welcomed (Collins and Grazin, 2008), critics have highlighted the explicit link of empowering self-care with the need to contain costs (Chapple and Rogers, 1999; Wanless, 2002) and raised concerns that self-care may be an excuse to reduce professional care (Kirkip, 2008). The paucity of research in this area has been highlighted, with outstanding questions including the need to understand patient preferences about changes in healthcare delivery, specifically their willingness to engage in 'partnership', and the barriers to change in professional practice (Bury, 2004).

2.5.2 Inter-relationship of professional and self-management

Glasziou et al. describe the complementary and evolving roles of periodic professional reviews and on-going patient self-monitoring (Glasziou et al, 2005). A newly diagnosed condition is assessed and brought under control with professional support, before the patient assumes responsibility for self-management as a stable maintenance phase is established. Critical to the effectiveness of self-management in the maintenance phase is the prompt recognition of, and appropriate response to deterioration.

Degeling et al. outline the need for patients to be informed, to be consulted and involved in decision-making on their care and to enter agreements with providers (Degeling et al, 2006a). They propose a model (see Figure 2) which delineates three stages of LTCs (at risk, with LTC, complex co-morbidities), and recognises the variation in the partnership between patients and their professional carers in three service modalities (self-management for health, care management, and case management). They also describe a 'support' area between patient self-care and professional management in an adaptation of the LTC pyramid which *"extends the constituent elements of the DoH service model beyond clinical and self management to include also support"* (Degeling et al, 2006a).

Figure 2. A Model for Long Term Conditions (reproduced with permission (Degeling et al, 2006a))
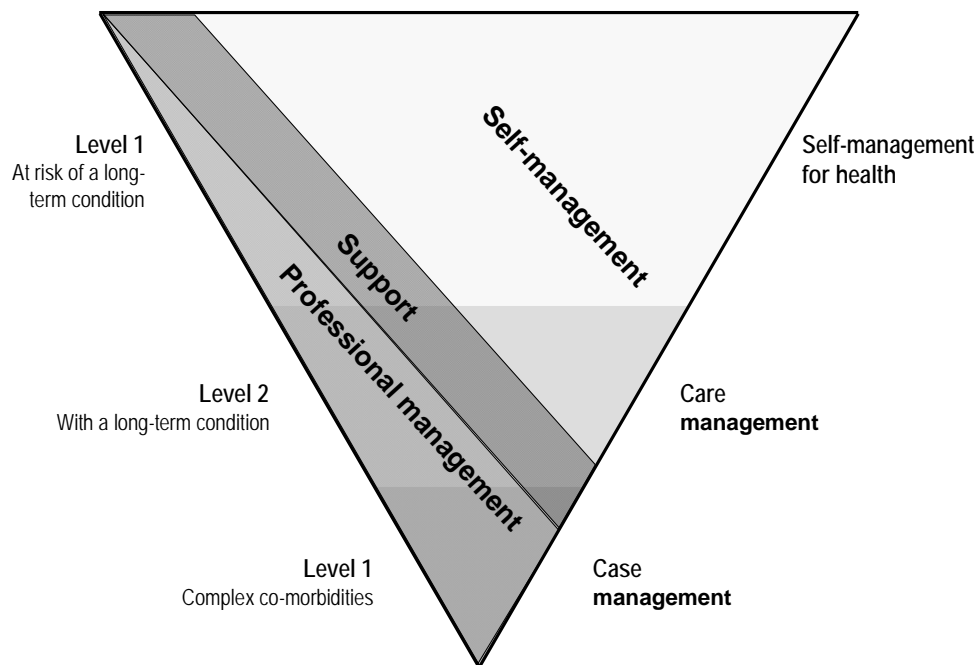
The intention is to *"invite detailed consideration of the types of support that will be provided at each level"* (Degeling et al, 2006a) which resonates with Kennedy's call (see Figure 3) for a whole systems perspective to self-care (Kennedy et al, 2007). Informed, confident patients seek help when needed from a professional trained in patient-centred care, working within a responsive health service (Kennedy et al, 2007).

Figure 3. A whole systems approach to supported self-care. (Reproduced with permission (Kennedy et al, 2007))

	Patient	**Professional**	**Structure**
Strategy	Improve information	Change professional response	Improve access to services
Specific method	Work with patients to develop information that is: ▪ Relevant ▪ Accessible ▪ Uses lay and traditional evidence based knowledge	Promote flexibility in professional response through: ▪ Patient centred approach ▪ Negotiation of self management plan with patients	Change access arrangements: ▪ Use patient-professional contacts to discuss access arrangements ▪ Allow patients to self refer based on their need for advice

A recent report on health literacy by the National Consumer Council identified many problems (Sihota and Lennard, 2004). People in the greatest need may be the least likely to have access to information, and the attitudes of health professionals can be a major barrier to participation in decision-making (Caress et al, 2005; Coulter and Rozansky, 2004; Sihota and Lennard, 2004). Inflexible out-patients' appointments or poor access to primary care services can prevent timely support.

2.6 Patient and public involvement

There is a policy intention that all changes in health service delivery, such as those proposed to improve care for people with LTCs, should be developed in consultation with patients (Department of Health, 2004f).

The concept of patient involvement has gathered momentum since the NHS Plan. Its declared vision of 'a health service designed around the patient', stated that patients must have more say in their own treatment and more influence over the way the NHS works (Department of Health, 2000b). Subsequent policy has reinforced both these ambitions (Department of Health, 2004f; Department of Health, 2006a; Department of Health, 2007c) which continue to be a priority for NHS reform (Brown, 2008).

2.6.1 Public involvement at all levels of the NHS

The intention is that there will be increasing emphasis on devolving decision-making to as near the point-of-delivery as possible in a partnership between commissioners, service providers and patients (Department of Health, 2004f; Department of Health, 2006a; Department of Health, 2007c). Despite this policy drive, and a succession of initiatives (e.g. Community Health Councils, the Patients' Charter (Department of Health, 1991), Patient Forums (Department of Health, 2000b), Patient Advice and Liaison Services (Department of Health, 2001a), which have sought to ensure that local views inform the development of local services (Department of Health, 2004f), recent reports have concluded that patient awareness of local changes and involvement in planning is currently limited (Audit Commission, 2004; Department of Health, 2007b). Amongst other criticisms, the complexity and lack of independence of current arrangements, poor integration into systems for service improvement, and limited resources have been highlighted (Baggott, 2005), and raised concerns that unless such issues are addressed the new Local Involvement Networks (Patient and Public Empowerment and Commissioning and Management Systems, 2007) will be similarly ineffective (Hogg, 2007).

2.6.2 Individual and citizen involvement

The distinction between individual patient involvement and public involvement as a citizen is widely described (Baggott, 2005; Coulter, 2006; Florin and Dixon, 2004), and resonates with the three tiers of representation described by Williamson: i) individual patients who know about and can describe their own experience of healthcare; ii) group

members who are aware of the experiences of other patients with similar conditions; and iii) patient advocates who have a general and abstract knowledge of strategic, ethical and policy issues (Williamson, 2007).

Coulter describes the different potential benefits of patient and public involvement (Coulter, 2006):

- Patient involvement in self-care aims to ensure appropriate treatment and care, to improve health outcomes, to reduce risk factors and prevent ill-health, to improve safety, and to reduce complaints and litigation.

- Public involvement as a citizen aims to improve service design, to determine priorities for commissioning, to manage demand, to meet expectations, and to strengthen accountability.

The degree of patient involvement is dependent on various factors, including individual factors such as patients' desire and ability to be involved (Thompson, 2004), professional attitudes (Thompson, 2007) and structural factors such as the methods used to promote public involvement (Florin and Dixon, 2004). In addition, the preferred level of involvement may change over time depending on the severity of the illness, and the degree of trust in the professional (Thompson, 2007). There are many challenges to enabling public involvement including overcoming limited knowledge of the structures and jargon of the NHS, exacerbated by the pace of change (Thompson, 2004).

2.7 Understanding workforce change

As the earlier description of new roles illustrates, the evidence base is growing about the clinical effectiveness, safety and acceptability of individual new roles which are accompanying the shift of care from secondary to primary care. Our study sought, however, to understand the process of planning and implementing these roles as part of new ways of delivering care, with the aim of producing guidance on effective models of service development. We therefore also needed to consider the literature on broader workforce change and service reconfiguration.

Sibbald et al (Sibbald et al, 2004) offer a description of the different forms reconfiguration can take - an approach which goes beyond questions of the functions and outcomes of single roles (see Table 1). Changes can be made to roles within a specific service, or at the interface between services.

The authors point out that healthcare organisations are already complex systems, which are often made more complex by skill mix changes potentially fragmenting services and work roles and making co-ordination of care difficult and costly. They call for further research about general patterns of workforce change and their wider organisational implications.

Table 1.   Organisational processes underpinning skill mix (Sibbald et al, 2004).

Context	Change	Description	Example
Within a given service	Enhancement	Increasing the depth of a job by extending the role or skills of a particular group of workers	Nurse-led primary care clinics for asthma Specialist Hospital at Home services for patients with COPD
	Substitution	Expanding the breadth of a job, by working across professional divides or exchanging one type of worker for another	Nurse practitioners undertaking minor illness clinics in place of GPs
	Delegation	Moving a task up or down a traditional uni-disciplinary ladder	Delegation of specialist care to a non-specialist
	Innovation	Creating new jobs by introducing a new type of worker	GPwSIs, community matrons
At the interface between services	Transfer	Moving the provision of a service from one healthcare sector to another	Substituting community for hospital care
	Relocation	Shifting the venue (but not the people) from which a service is provided from one healthcare sector to another,	Running a hospital clinic in a general practice setting
	Liaison	Using specialists in one healthcare sector to educate and support staff working in another sector	Hospital 'outreach' facilitators in general practice

2.7.1 Innovations in healthcare organisations

The literature on the implementation of innovations in healthcare organisations is useful in understanding workforce change. Implementation of 'innovations' refers to the process that organisations undergo as they develop and implement new products, administrative arrangements, services and programmes (Van de Van et al, 2008).

> "[Innovation in service delivery and organisation can be defined as] *…a novel set of behaviours, routines and ways of working, which are directed at improving health outcomes, administrative efficiency, cost-effectiveness or the user experience, and which are implemented by means of planned and co-ordinated action"* (Greenhalgh et al, 2004b).

There is a large literature about innovation in healthcare and in other organisations but the review and interpretation of it is problematic. As Greenhalgh et al emphasise in their comprehensive recent review of the literature on diffusion of innovations in healthcare (Greenhalgh et al, 2004a; Greenhalgh et al, 2004b), research on innovations has been carried out

within different traditions, employing different methodologies, epistemological assumptions and interpretive frameworks. This makes it difficult to establish a coherent evidence base, identify gaps in knowledge and establish the implications for good practice in service development. Nevertheless, some key implications are emerging from this review and other recent work which are relevant to our study (and to other research on service change) and we briefly summarise some of the main ones here:

- An emphasis that in complex organisations like health services, the process of organisational change is unlike the linear process of progression through distinct and predictable phases described in much of the earlier innovation research. Instead, it is non-linear, and subject to a range of variables which interact to influence outcomes. The process is, however, not random, but shaped by an underlying organisational logic, which has to be understood in order to manage the process (e.g. (Van de Van et al, 2008)).

- An innovation is more likely to be adopted if it has certain attributes: relative advantage; simplicity and clarity of goals and priorities; quality and coherence of policy; rigorous evaluation and defined goals and milestones; low complexity; trialability; observability; re-invention; and codifiability ((Fleuren et al, 2004; Greenhalgh et al, 2004b; Grol and Wensing, 2005; Gustafson et al, 2003; Pettigrew et al, 1994; Rogers, 2002).

- Of particular importance is the concept of 'relative advantage', described as the *sine qua non* of innovation (Greenhalgh et al, 2004b). This means that all key players have to recognise and acknowledge that the proposed changes have a clear advantage over current practice in terms of effectiveness or cost-effectiveness. Perceptions of relative advantage are socially constructed (e.g. (Fitzgerald et al, 2002; Fitzgerald and Dopson, 2005)).

- It is essential to address issues arising from professionalised organisations (e.g. the strong influence of health professionals, particularly doctors) and the effect of boundaries between health professions in impeding change (e.g. (Ferlie, 2005; Ferlie et al, 2005)).

- Local context is very important (e.g. (Sheaff et al, 2003)): the structure and function of organisations are heavily influenced by their political, socio-cultural and historical environment.

- Organisational culture(s) may be highly influential: although the concept of organisational culture is both contested and controversial and there are debates about whether culture change is either feasible or desirable (e.g. (Alvesson.M and Willmott, 2002; Scott et al, 2003), there is broad agreement (e.g. (Davies and Nutley, 2000)) that policy documents are placing greater emphasis on 'culture change' as an integral part of service change.

Against this background of the broader literature on organisational change and innovation in healthcare and other organisations, our particular focus was on the dynamics around workforce change. We therefore looked at the literature around three areas: the sociology of professional boundaries; increased managerialism and 'New Public Management'; and the impact of a market-based economy on relationships within health care organisations.

2.7.2 The sociology of professional boundaries

The sociology of professional boundaries sees workforce change as a political process with professions and occupational groups negotiating and contesting territories of clinical and healthcare work. This discipline has produced a substantial literature, which, apart from suggesting a theoretical and methodological approach to the contemporary study of workforce change, also provides a historical perspective.

The establishment of professions

An early influential writer is Elliott Freidson (Freidson, 1970) who outlines a sociological analysis of the strategies that changed medical occupations into a profession by restricting access to new members through education and socialisation, establishing a protected body of knowledge, and achieving license to self regulate and protection from competition. The way rules of incorporation are established and managed, rather than the nature of the work, is the key factor in the formation of professions.

Freidson's work applies the Weberian concept of 'closure' to the study of professions and invites a view of professions as stable and monolithic groups. Broadly speaking, clinical work can be seen as organised according to a hierarchical pattern based on criteria of 'specialisation', with a relatively small group of secondary care clinical 'specialists' at the top of the ladder, and larger groups of 'generalists' (e.g. GPs, primary care doctors and nurses and paraprofessionals occupying middle rungs, followed by healthcare assistants, and, at the bottom, patients and unpaid carers (Nancarrow and Borthwick, 2005). The hierarchy is structured by the interests of medical professions, with the work of nurses and allied health professionals, healthcare assistants, patients and carers controlled by the more powerful medical groups (Larkin, 1983).

Skill mix and the negotiation of boundaries

This system is however dynamic, not static. Nancarrow and Borthwick (2005) describe a process of boundary change within and among groups, which reflects the typology of skill mix outlined by Sibbald et al referred to above (Sibbald et al, 2004). With the advance of medical technology, a process of specialisation and diversification within disciplines at the top end of the hierarchy is taking place, as new areas of work are being identified and occupied. With this 'upward' move space is opening up for other groups to move into territories previously occupied by specialists. This process is characterised by routine and less skilled aspects of a role being discarded and delegated to lower status groups (Larkin, 1983). The changes in disciplinary boundaries across the vertical axis of the 'hierarchy' are

accompanied by changes in boundaries between groups with similar levels of training and status at similar 'rungs' of the ladder

Pursuing the theme of fluidity in the way boundaries between professional 'ownership' of work are drawn and redrawn, Abbott (Abbot, 1988) suggests that occupational groups compete for 'jurisdiction' of particular work domains in three spheres: the legal sphere; the public sphere; and the sphere of everyday work. The latter is the focus for our study. Studies of the negotiation of professional boundaries in the workplace, which capture differentiation and allocation of tasks within and between professions and occupational groups as the conditions of clinical work change (e.g. (Sanders and Harrison, 2008), resonate with our study, which examines a shift towards disease specific management in service settings occupied by generalists such as GPs. These trends open up an 'intermediate' space between 'specialist' and 'generalist' domains. Opportunities emerge for new roles and patterns of work to be negotiated in this space, for established groups to diversify and move into new territories, and new groups to be formed. It also opens up a new area of contest and negotiation between groups such as GPwSIs, specialist nurses, community physicians and community matrons, whose areas of work potentially overlap.

The literature of professional boundaries is dominated by descriptions of combat, with authors employing terms such as 'occupational imperialism' (Larkin, 1983), 'jurisdictional disputes' (Abbot, 1988), and describing strategies of usurpation and exclusion (McDonald KM, 1995). Whilst there is evidence of negotiation, agreement and accommodation, this has been described in cases of horizontal boundary changes among groups with similar levels of training and status (Kreckel R, 1980). The history of the professions, seen from a sociological perspective, thus does not augur well for the shift of care for LTCs from secondary to primary care settings, as this is predicated on integration and collaboration between clinicians with different and often competing interests. In addition, neo-liberal principles introduced in the NHS in the last three decades, create new conditions for professional boundary work as increased managerial control challenges established professional interests, by emphasising allocation of work on the basis of cost-effectiveness, rather than narrowly specialist skills and expertise.

2.7.3 Increased managerialism or 'New Public Management'

A central tenet of the NHS modernisation agenda is a strengthening of managerial functions, coupled with increased reliance on market mechanisms to ensure strategic development towards cost effective service arrangements.

This policy is shaped by widespread changes in public administration. Since the 1970s and 1980s, public administration of centralised state monopolies has been challenged on the grounds of rising costs and lack of responsiveness to public needs. In a globalised world, with citizens cast as increasingly informed consumers of services, national, state-run services built on Weberian principles of bureaucratic top-down command and control

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are changing. New forms of management are emerging which aim to ensure cost containment, increase cost-effectiveness, flexibility, devolution of decision-making to local levels, and increased patient-as-consumer power through exercise of choice between a range of providers.

These new forms of management centre on the introduction of principles from the private sector into healthcare and other public services. A key principle is the disaggregation of services into clearly defined and auditable parts which can be performance-managed and controlled. An associated trend is the move away from central planning with top-down bureaucratic implementation of coherent strategies, to 'the market' which is intended to achieve the desired changes through competition between providers, and through incentives to commission for highest quality at the lowest price. An important consequence is a distinction between provider and commissioning functions within healthcare organisations (Department of Health, 2005a; Department of Health, 2007e).

The term 'New Public Management' (NPM) has been coined to describe this trend towards marketisation of public services, particularly evident in the US, UK, New Zealand and Australia from the 1980s onwards (Hood, 1991). David Osborne and Ted Gaebler in *Reinventing Government* say of change in American government that *"the reforms represent a paradigm shift."* (Osborne and Gaebler, 1992). Since the 1990s a debate has been conducted about whether NPM does indeed represent a paradigm shift, or whether it is merely the old and well worked principles of management dressed up in a new context. While the jury is still out on this debate, there is increasing interest in empirical research exploring local variations of the central theme of a new style of public services management.

New Public Management in the UK

In the UK, the market as a mechanism for service development is currently given most prominence in English and, to a lesser extent, in Welsh, healthcare policy. The present form of healthcare organisation must be seen against a background of continuous healthcare reform since the 1990s, when the Thatcher government introduced an 'internal market' in the NHS with the stated aim of driving up quality through competition. The reform was based on a division between purchasing and provision of services. Purchasing was based on a specification of quality and value for money of services, with those services presenting the best case allowed to tender. General practice fundholding was a central element in the reforms with the intention of 'kick starting' the reforms and applying pressure to reduce the share of the healthcare cost traditionally consumed within secondary care. Unintended consequences of these reforms in terms of inequity of service access were identified, with a 'two tier' service benefiting patients of strong fundholders at the expense of patients in non-fundholding practices (Dixon, 1994).

With the coming to power of the New Labour government in 1997, fundholding was abolished, but primary care driven service development was retained. Policies were introduced for a system of 'commissioning', which aimed to facilitate a more strategic process of service development

for improved and equitable healthcare at population levels. According to the policy documents, commissioning involved assessment of population needs, and the development and contracting of services to meet those needs (Department of Health, 2004e). The policy also encouraged a partnership approach to service development, through a 'third way' approach to management through networks, a stronger emphasis on planning and an evaluation in terms of 'what works' (Boyne et al, 2001).

At the time of our study, organisational reforms were being introduced in England and Wales to facilitate commissioning as a driver of healthcare developments. The reforms had two elements: one was the merger of PCOs to create commissioning organisations with stronger commissioning 'muscle', and the concentration of commissioning skills (Department of Health, 2005a; Department of Health, 2006b), whilst the other was a clearer demarcation of commissioning and provider functions within PCOs, though the initial intention that PCOs should divest themselves of provider functions completely was later retracted. In England, but not in Wales, commissioning functions were devolved to local level through Practice Based Commissioning (PBC: A system which gives English GP practices indicative budgets and responsibility for commissioning care for their practices' population) (Department of Health, 2004e). The policy of contestability – giving non-NHS providers access to English healthcare markets – introduced an extra element of competition, designed to drive improvements in quality and enhance patient choice.

A question for our study was the extent to which, and how, commissioning and market-based organisation of healthcare impacts on professional boundary work.

2.7.4 Relationships in a market-based economy

Broadbent and Laughlin outline three different principles – 'clan', 'bureaucratic' and 'market' – for the organisation of medical care (Broadbent and Laughlin, 2002). These principles represent different ways of 'getting things done' in the way they structure relationships between members of the organisation, though in the complex reality of everyday work, several types of relationships are at play simultaneously. Market reforms based on principles of commissioning, structure relationships between healthcare professionals in new ways and potentially alter the conditions of boundary work (see Table 2).

Table 2.   Summary of the three principles for the organisation of medical care (Broadbent and Laughlin, 2002)

(Note: Although tabulated as independent 'principles' the relationships described overlap and will invariably co-exist)

Principle	Description	Implications
Clan	Behaviour is co-ordinated through ritual and shared norms and values. This is the predominant form of organisation for many professional groups, including doctors.	• Clans lend themselves to informal arrangements about new roles made between members of the same profession, specialty or network. • These arrangements are not always transparent, and can be exclusive of new people and ideas.
Bureaucratic	Decision-making is hierarchical and embedded in rules and processes. This form of organisation is exemplified by the 'old style' NHS.	• Arrangements regarding new roles have to be done with regard to due process. • Although they are more transparent and open to arguments than a 'clan' arrangement, they can lose sight of the end point of new work roles.
Market	Relationships are based on the *contract* between the commissioner (buyer) and the provider of services, specifying what is to be delivered at what price. This form of organisation is an increasing feature of the 'new style' NHS.	• Relationships rest on an agreement about the product to be delivered, in a specified time scale and at a specified cost. (e.g. reduction in COPD admissions by 31st March as a result of a GPwSI service) • This agreement is sanctionable, and the contract can be withdrawn if the product is not delivered or undeliverable, or if a provider with a service representing better value for money appears. • A contract-based system of healthcare organisation is therefore based on measurable outcomes and introduces a focus on cost efficiency.

The increasing importance of market-based service arrangements in the English, and to some extent Welsh, health services, based on formal contracts between providers and buyers of services, has altered the conditions for boundary work among healthcare groups. Claims to jurisdictional privilege increasingly need to be argued in terms of accomplishment and value for money or 'organisational efficiency' (Sanders and Harrison, 2008), and are subject to managerial control and monitoring. Collegial relationships and the place of individuals in an organisation are intended to become secondary to the overall aim of best value for resources invested. This implies a transparent and technical/rational process of identification of organisational needs and commissioning of the roles which meet that need. In theory, it reduces the power of professions to make arrangements based on their interests and leads to a 'breaking down of boundaries' between professions and occupational groups, and facilitates

service arrangements which are flexible and formed around the needs and interests of patients (Department of Health, 2004c).

The question of whether stronger managerial control implies a loss of professional autonomy and power has received much attention in the literature.   Some argue that a process of 'proletarisation' (McKinlay and Stoeckle, 1988) and 'deprofessionalisation' (Haug, 1973) of the medical profession is taking place, through the definition of and allocation of work defined by managerial strategy, consumer pressure and the market economy.   However, as Nancarrow and Borthwick (2005) argue, there is little sign that professional boundaries are disappearing in the new UK NHS context.   Freidson (Freidson E, 1984) argues that what has occurred is the emergence within professions of 'knowledge elites', who maintain the autonomy and control of the profession in the new context, by regulating the activities of 'rank and file' groups with reduced autonomy, for those who carry out increasingly routine work.

Fournier (Fournier, 2000) similarly argues that professions have survived previous organisational changes potentially eroding their power and autonomy, notably the introduction of the NHS as a public service 'bureaucracy'.   She argues that professions establish their territory, not just through strategies of boundary work, but also by constructing a field of expertise using current language, ideology and knowledge to assert their 'natural' ownership in changing contexts.   The question for our study was whether, and how, these dynamics played out in the process of shifting care for LTCs from secondary to primary care settings, and what the implications were for workforce change.

3 Aim and Objectives

3.1 Aim

To understand and compare the process of workforce change in respiratory services and the impact on patient experience (specifically, but not exclusively, focusing on respiratory General Practitioner with a Special Interest (GPwSI) services) in a theoretically selected sample of Primary Care Organisations (PCOs), in order to derive models of good practice in planning and implementation of a broad range of workforce issues.

3.1.1 Objectives

We sought to:

1. Identify key drivers of respiratory service reconfiguration in a sample of PCOs.

2. Identify the factors (including local context, knowledge/evidence base, available resources and perceptions of clinical roles) which shape the planning and implementation of workforce change.

3. Understand the infrastructure, support and training required successfully to achieve appropriate workforce change in delivering respiratory care.

4. Examine the relationship between changes in respiratory services and patient experience when respiratory services are reconfigured.

5. Examine patients' awareness and perception of workforce changes in the context of overall management of their respiratory disease.

6. Develop guidance on effective models of implementing workforce change to deliver services for people with LTCs.

4 Methods

4.1 Study overview

Our study, undertaken in 2006 and 2007, proceeded in four phases (see Figure 4). Using a design modelled on organisational process research (McNulty and Ferlie, 2002), we conducted a comparative prospective case study in four PCOs selected to show variation in respiratory service workforce change.

Figure 4. Flow diagram of the four phases of the study procedure

	All 322 PCOs in England and Wales

Recruitment to represent a wide spectrum of attitudes to the reconfiguration of respiratory services

1	**Initial screening interviews**	**30 PCOs**

Selection based on current proposals for reconfiguring respiratory services encompassing a mix of service models (some including a GPwSI), demographic profiles, and service priorities.

2 Case studies   **4 PCOs**
+ 4
involved in merger

Baseline interviews with 4-6 key stakeholders in each PCO
Collection of relevant documents/routinely collected data
Regular telephone or e-mail contact
Interim interviews and in-depth examination of events
Exit interview with key stakeholder(s)

3 Patient perspective

Illness diaries with 6-8 respiratory patients in each PCO
+ serial interviews
Focus group in each PCO

Supplementary interviews (if necessary) to check generalisability of key themes

4 National multidisciplinary workshop

Discuss and interpret emerging themes
Develop guidance on best practice

4.1.1 Ethics and Research Governance approval

Our study was undertaken with the approval of South-East Multicentre Research Ethics Committee. Research governance approval was sought from 316 of the 322 PCOs in England and Wales for whom contact details were available: approval was granted by 259 from which we selected PCOs to participate (Kielmann et al, 2007).

4.2 Phase I: Screening interviews

4.2.1 Recruitment of PCOs for screening interviews

We purposively sampled PCOs in England and Wales to encompass a broad spectrum of plans for the reconfiguration of respiratory services. A specific criterion was to include a range of attitudes to the role of a respiratory GPwSI.

We initially approached PCOs based on their responses to our previous survey conducted in 2004 (Pinnock et al, 2005), which had requested information about plans for developing respiratory care, and specifically about their attitudes to the role of GPwSI, both in the context of respiratory care and more generally. This provided a pool of PCOs, whom we knew to have a respiratory GPwSI in post, or whose plans for development of respiratory services included the possibility of a GPwSI. We were also aware of PCOs who favoured the GPwSI role in other contexts, but preferred alternative models for the delivery of respiratory care. Our survey had also made us aware of the range of alternative models that we needed to encompass (principally nurse-led services including the emerging role of community matrons). We were also keen to recruit some PCOs who had indicated that GPwSIs and/or developing respiratory services were not a priority.

A further source of information was the list of PCOs who had responded to the publication of the GPIAG Respiratory GPwSI resource pack (General Practice Airways Group, 2005), by expressing interest in receiving more information, and agreeing that they could be contacted for research purposes. In addition, we purposively approached some PCOs who had not responded to our survey.

We also used information from interviewees about innovative service models, or particularly challenging scenarios of which they were aware to identify further PCOs.

We continued to recruit until we reached saturation in terms of the models described. Our a priori strategy was to ensure that we included examples of PCOs that had (or were planning) a GPwSI service; had (or were planning) a nurse-led service; were implementing a community matron service; were planning to up-skill primary care; were planning a consultant out-reach service; or had no plans for developing respiratory services). We sampled PCOs at different stages of respiratory service development (from early stage of planning to an established service). In addition we ensured a

geographic spread by recruiting PCOs from around England and Wales with a range of population size and demography.

We approached PCOs by letter between February and June 2006, followed up by a phone call, requesting a 45-minute telephone interview with the person(s) responsible for driving the reconfiguration of respiratory services. In PCOs not planning reconfiguration of respiratory services we asked to speak to the person responsible for other comparable chronic disease services.

4.2.2 Semi-structured telephone interviews

Based on our previous work, (Moffat et al, 2006; Pinnock et al, 2005) and our understanding of the literature relating to the management of LTCs (Department of Health, 2004c; Department of Health, 2005c; Gask, 2005), and the evolution of clinical roles (Department of Health, 2003a; General Practice Airways Group, 2005; Royal College of General Practitioners and Royal College of Physicians of London, 2001; Williams et al, 2002), we devised a semi-structured interview schedule (Appendix 1), collecting data on:

- Size and demographics of the PCO.

- Current priorities and preferred models for configuring services for the care of long-term diseases.

- Person(s) responsible for the changes, and proposed management arrangements for new services.

- Key drivers: e.g. respiratory champion, pressure on secondary care, primary care collaborative, strategic development of care for LTCs. Information was requested about any available local data (referrals, waiting times, asthma and COPD admissions, prescribing costs) used to inform decisions.

- Preferred model of care for respiratory disease: e.g. respiratory GPwSI, Hospital at Home scheme, managed care, supporting GMS contract, secondary care outreach.

- Sources of information and support.

- Proposed training programmes for staff in reconfigured posts.

Interviews were conducted by one researcher and we continued to recruit PCOs until we reached saturation (up to a maximum of 50 interviews). Extensive notes were made on pre-structured forms and interviews were audio-recorded (apart from interviews 1 and 2 which were not recorded for technical reasons). Recorded interviews were fully transcribed.

4.2.3 Data analysis

Analysis of interview data was carried out by two researchers with discussion regarding emerging frameworks and coding strategies taking

place at regular intervals with other members of the team. The coding frame is given in Appendix 2.

Data analysis was iterative and emerging themes were used to inform the subsequent interviews. We adopted the thematic approach to analysing qualitative data described by Ziebland et al (Ziebland and McPherson, 2006).   In addition to drawing on relevant frameworks in relation to the role of specialist services, and the levels of care of people with LTCs (Department of Health, 2004c; Gask, 2005), we searched specifically for unanticipated themes and deviant cases.   Emergent themes were discussed by all members of the multidisciplinary team during a project workshop.

We devised a matrix to examine the association between clinical involvement and roles of the specialist services.   The degree of involvement of PCO managers, secondary and primary care clinicians was categorised as 'no / limited / substantial involvement', and commitment of a specialist service to clinical, strategic and educational roles was categorised as 'no provision / minimal evidence / specific description / high priority'.   Tables 3 and 4 give details of the grading criteria.

Table 3. **Criteria for categorising the involvement of PCO managers, secondary and primary care clinicians in reconfiguring respiratory services**

Grading	Criterion	Examples
No involvement	The professionals were not mentioned at all in the interview, or only as users of the service or employees of the service. No description of any contribution to the development of the service.	GPs referring patients to the service. A respiratory specialist nurse providing clinical care.
Limited engagement	The professionals were mentioned as stakeholders in the redesign of the services, but it was unclear what, if anything, they had contributed.	A GP committee member who had not attended any meetings. A hospital trust manager 'copied in' to the minutes of meetings. 'Practice respiratory leads' with no described role.
Substantial engagement	Specific (often named) individual(s) with specific examples of contribution.	Contributing to a local network. Championing the cause amongst colleagues. Leading an audit process.

Table 4. **Criteria for categorising the functions of the specialist service**

Services could be clinical (e.g. 'Hospital at Home' services, pulmonary rehabilitation), educational (e.g. respiratory training for community nurses, mentors working in general practices) or strategic (e.g. involvement in a respiratory network, designing care pathways)

No provision	The potential role of the specialist service was not mentioned at all in the interview, or was described as non-existent.	
Role mentioned	A role was mentioned but with minimal/no corroborative evidence, or described by the interviewee as 'limited'/'inadequate'. Use of an ineffective strategy or evidence of poor engagement.	Small scale 'pilot' pulmonary rehabilitation service. Dissemination of written guidelines. Non-attendance at committee meetings.
Role described	Aspects of the service were discussed in more detail with specific examples	Establishment of planned early discharge service. In-house training for primary care. Active local respiratory network.
High priority role	A well-defined existing/proposed service, usually with development plan and evidence of on-going commitment to the service. Issues of sustainability were addressed, though not necessarily solved	Secure funding source to maintain a service Well defined development plan, with a vision for the future. Training to ensure sustainability.

4.3 Phase II: Case studies

4.3.1 Selection of PCOs for case studies

Using our findings from the Phase 1 interviews we recruited four case studies in autumn 2006 for in-depth investigation over one year. We opted to study the development of services within PCOs because they are the bodies with responsibility for commissioning (and until recently also providing) respiratory care. This ensured that we encompassed the broader picture of care for people with respiratory disease, aspects of which might be overlooked if we had focused on specific specialist services. Our previous work had confirmed that this was the level at which GPwSIs were operating.

In addition to the pivotal a priori selection criteria (GPwSI/GP role and their training needs, preferred service model, maturity of plans), we included two factors (organisational change, and professional boundaries/teamwork), which emerged strongly from the interviews as determining the progress with reconfiguration. The size of the PCO, the demography of the area, the projected merger and financial status were other factors considered.

1. The role, or lack of role, for a respiratory GPwSI or 'interested' GP and the maturity of the service. We selected two PCOs with, or planning a GPwSI service. One of the GPwSIs was undertaking a formal training programme, (Bradford and Airedale Teaching PCT, 2008; Education for Health, 2008), the other was accredited by portfolio (Gruffydd-Jones, 2005). Of the other PCOs, one had 'an interested GP', the other appeared to have minimal GP involvement in the reconfigured service.

2. The favoured model for provision of respiratory services. We selected two PCOs with GPwSI services, one PCO with a formally commissioned nurse-led service and one PCO with a single specialist nurse and more traditional general practice care. As one of the PCOs with a GPwSI service was about to merge with either two or four neighbouring PCOs (which had a range of GPwSI and nurse-led services), we were aware that this would offer further examples of these models of care.

3. Maturity of plans. One of the GPwSI services and the nurse-led service were both established, one GP was just embarking on a formal training programme. The final PCO was in an early stage of developing respiratory services.

4. Organisational change (specifically the impending reorganisation of PCOs, and the development of commissioning within a market economy).   At the time of selection, details of PCO reorganisation had not been announced, but we selected a PCO which expected to merge with two, or possibly four, neighbouring PCOs.

5. Professional boundaries and importance of teamwork. We selected one PCO which appeared to have a robust respiratory team and another where we understood there were some professional boundary problems.

We used a spreadsheet to collate the information about these criteria for all the Phase I PCOs, and discussed the selection of case studies with the multidisciplinary advisory group.

We initially approached five PCOs, one of whom decided after some deliberation that they were unable to help. By this time the PCO merger plans had been announced, and it was apparent that one of our case studies was to merge with four adjacent PCOs, one of whom had an established respiratory GPwSI in post, one had a GP who had undertaken training for a GPwSI role, but funding had not been secured for her post, the other two had nurse-led services. In view of the importance of organisational change in determining development of services, and the opportunity to observe two further GPwSI services, we opted to recruit all five of the merging PCOs, rather than recruit additional case studies from our pool of screening interviews.

We thus commenced our case studies with eight PCOs which contracted down to four over the course of the study.

4.3.2 Initial visit to PCOs and baseline interviews

At an initial visit to each of the case studies, we undertook semi-structured interviews with key stakeholders in the local respiratory service, selected to represent perspectives on the service from different positions and organisational levels in the system (strategic, middle management, service levels and clinicians), in both PCO, primary and secondary care services. Interviews were conducted face-to-face or by telephone, audio-taped, and lasted approximately one hour.

The content of the interviews was customised to the circumstances within the PCO and the role of the interviewee, but the overall aim was to build on the 'snap-shot' provided by the initial telephone screening interview to develop a detailed picture of respiratory services in the PCO and any proposed plans for development (Appendix 3). We collected data on:

- The current service, and any perceived strengths and weaknesses. Any data or local evidence to support these perceptions were discussed.

- Current local workforce issues such as numbers of doctors and nurses working in respiratory medicine, unfilled posts, skill mix arrangements and local problems with recruitment.

- The aims, and expected benefits, of the proposed service from the perspective of all appropriate stakeholders.

- The current plans for development and the progress to-date.

- Attitudes to the projected plans. These were explored to identify perceived advantages and disadvantages of the proposed model of care, alternatives either rejected or still under discussion.

- The evidence (including financial/clinical evidence, local/national data) used to inform proposed plans and any advice and support accessed.

- The factors perceived to be facilitating progress and actual/potential barriers to development.

- The immediate plans for making progress towards service reconfiguration. This might include any planned meetings, audit activities, training programmes, new staff appointments, planned explorations of available resources/advice/support agencies etc.

- The training needs, from the perspective of the healthcare manager responsible for developing the service and, importantly, from the perspective of the GPwSI.

Further interviews were arranged if, for example, an individual or group of people was identified during the initial interviews as having an important role, or strong feelings which might impact on the development of the service. Any documents identified as relating to the history of the service to date were requested.

4.3.3 Prospective examination of planning process

We undertook regular updates with key stakeholders usually by short telephone interviews. We aimed to capture the unfolding process over the course of one year to provide a full picture of events and the organisational dynamics involved in service change. In the PCO involved in the reconfiguration of boundaries in October 2006, we arranged additional interviews with key management and clinical personnel from the neighbouring PCOs to explore the situation before the merger, to enable us to understand the impact on respiratory services.

Selected events in the planning process (e.g. formal meetings, submission of business cases for funding or service change, lack of decision-making, results of audit reports, training events, crises and disputes) were monitored and updates obtained. We explored the impact of the event on the development process in interviews with key players. Key documents were requested, and news items identified from local and national web-sites. New people identified as involved in the project were approached and interviewed until information about each event was saturated and the perspectives of key players had been elicited.

We discussed training programmes undertaken, practical experience gained, conferences attended, mentorships and personal learning pursued with GPwSIs and other specialist clinicians. Details of any courses attended were requested.

4.3.4 Exit interviews

We undertook final face-to-face or telephone interviews with the key stakeholders in each case study at the end of the year to update on progress, and to explore their perception of whether or not the service had successfully addressed the intended aims, and whether there had been any unintended outcomes. Specifically, we asked GPwSIs and other specialist clinicians about progress towards accreditation, and explored the perceived benefits (or not) of the training undertaken.

4.3.5 Data handling and analysis

Interviews were transcribed verbatim and entered into NVivo 7 (QSR International. Doncaster, Australia).

The coding frame was established collaboratively by discussion. Integration of codes into themes and emerging analysis were discussed with the wider team and with key stakeholders, including at two multidisciplinary workshops.

We analysed these data by reading all transcripts and documents and constructing an initial coding frame from key issues which emerged across all interviews and documents (Appendix 4). All transcripts were coded. We then examined single codes across transcripts to explore how the same issues were expressed by different respondents, in different roles, at different points in time and across the four cases.

As analysis proceeded, codes were integrated into three overarching themes, which form the basis of this report (see background literature in Section 2.6). We explored how these overarching themes interacted in each case to shape the service development:

- Change.

- Commissioning and contracts, which included issues related to cost, audit, performance management and governance.

- Professional boundaries, which included personal relationships, training and accreditation.

Analysing process data involved extracting a variety of social phenomena as units of analysis from a continuous flow of events which unfold over time, at different organisational levels (e.g. conversations, perceptions, meetings, decisions or lack of them, documents, policy). The aim was to identify key units of analysis in context and detect patterns among them over time, and so build up an understanding of organisational dynamics driving the process of workforce planning (Langley, 1999). This was a complex task which requires continuous interrogation of evolving data sets.

Analysis proceeded in two stages (Huby and Rees, 2005):

1. A narrative description over time of the planning process from different perspectives, in each of the case study PCOs. This addressed the observational aspects of the brief (i.e. key drivers for workforce

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changes, key factors affecting service reconfiguration and their interaction with the planning process, the identification of existing staff competencies, and the delivery and effectiveness of training).   The approach taken allowed us to understand broad trends, and issues in workforce planning in terms of fine-grained descriptions of organisational process in each case study site (Gluckman, 1958; Huby, 1998; Langley, 1999).

2. Comparison between cases.   Having identified the key factors impacting on planning of workforce changes across the cases, we examined the dynamics of these factors in each case (Eisenhardt, 1989; Huby and Rees, 2005) allowing us to address comparative questions such as identification of best practice and the relevant weight of identified contextual factors.

Emerging themes and theories were checked for validity and generalisability by:

- Discussing themes with our multidisciplinary advisory group (which included the co-applicants and project collaborators).

- Discussing the emerging themes and theories at the national workshop involving a wider group of professionals and lay participants (including co-applicants and collaborators) allowing guidance on best practice to be developed.

- Using the conceptual underpinning and appropriate theory, outlined in our introduction (see Section 2.6) to support the analysis.

Case study data analysis was led by two researchers in regular discussion with other members of the multidisciplinary research team. Two study workshops, the first after the initial case study visits and a second before the exit interviews, supported this iterative process.

4.4 Phase III: Patient perspective

4.4.1 Sampling strategy

By using a range of recruitment methods, our aim was that an invitation should reach a broad cross-section of the population experiencing respiratory disease.   We considered the possibility of only approaching the minority of people, who had seen a GPwSI or other professional from a new specialist respiratory service, in order to obtain in-depth information about that particular service. However, PCOs are responsible for commissioning healthcare for whole communities, and we argue that specialist services should take responsibility for improving the quality of services provided to all patients with respiratory disease. Our previous work confirmed that respiratory GPwSIs are operating at PCO strategic level.   We, therefore, opted to capture the broader perspective and accordingly chose recruitment methods which not only included patients who had seen a GPwSI or attended a new respiratory service, but also encompassed the wider population of those with respiratory diseases.

4.4.2 Patient recruitment

In each case study area we recruited patients by advertising in the local press and distributing information leaflets and posters about the study via GP surgeries (both handed out opportunistically and through small mailshots), specialist respiratory services, outpatient clinics, pharmacies, and Breathe Easy groups. In all, we distributed 815 leaflets and 57 posters. We asked respondents to provide information about age, gender, experience of the healthcare services, type of respiratory illness, their mobility, and availability of transport to ensure that we sampled people with a range of profiles. Potential participants were then contacted directly, asked for consent and invited to take part in either an illness diary and telephone interviews or a focus group discussion.

4.4.3 Data collection

Data on the patient perspective were collected through three complementary approaches:

1 Illness diaries

We aimed to recruit six to eight patients in each case study PCO to keep an illness diary over a month and to take part in two short phone interviews during that time. These illness diaries were a record of symptoms in the context of the author's overall life situation, and the range of formal/informal support, information sources and healthcare services accessed. The benefits of using illness diaries as a research tool in providing clinically relevant information have been documented (Stensland P and Malterud K, 1999). These include using diaries as medical documentation, accessing patient insights and personal input into management and exploring the significance of medical diagnosis or chronic illnesses to the patient.

We chose this method as illness diaries are a recognised research tool for accessing people's insights into an illness and their 'internal dialogues' about an illness experience. The act of writing makes the respondents verbalise and articulate their experience and insights. In this study we combined illness diaries with semi structured telephone interviews. The illness diaries facilitated a respondent-centered exploration of the features of the respiratory condition and its management which were salient to the patient.

The diary instructions asked participants to find a convenient time each day when they could spend 5-10 minutes writing. Although they were free to write about anything they felt was important, we specifically encouraged them to record:

- How their respiratory illness had affected them on that particular day.

- Any symptoms due to their respiratory illness and any treatments they had used.

- Any advice and information they had read in magazines, on the Internet, seen on television or heard through any other type of media.

- Any discussion they had had about their illness with friends or family.

- Any consultations about their respiratory illness with their GP, nurse, hospital consultant, pharmacist or complementary therapist.

The instructions and a sample page from the diary are reproduced in Appendix 5.

2 Telephone interviews

Telephone interviews lasting up to 40 minutes were conducted at the beginning and end of the diary. The open–ended questions posed in the first phone interview aimed to explore participants' ways of dealing with their condition, within the context of their available service arrangements, and access to information and support. The second interview was adapted to reflect the illness events noted by the participants in their diaries, and was discussed in the context of local services and planned development. The interviews were conducted by one researcher.   Key issues addressed (see Appendix 6) included:

- Dealing with the respiratory condition on a day-to-day basis, including how the patient managed their own care, what types of support they had at home and accessed locally.

- Details, context and motive(s) for any consultations for respiratory conditions.

- Sources of advice and information accessed and motives for seeking advice (e.g. Internet sites, news articles, friends, family and local/regional organisations).

- Patients' perspectives, expectations and priorities of the service and its outcomes.

- Their awareness of the service system and possible change (specifically the GPwSI service), and their experience of changes in care provided.

3 Focus groups

We arranged a focus group in each of the PCOs (excluding the very rural area where a single focus group was impractical for geographical reasons). Groups included some patients who had contributed to the illness diaries as well as additional participants to broaden the perspectives.   Convenient venues were chosen and travel expenses reimbursed.   The discussions were audio-taped with consent and lasted about an hour.

Focus group discussions were facilitated by two researchers who were familiar with the service arrangements in the locality.   Broad, open-ended questions were developed as stimuli for discussion in each focus group

(Appendix 7). These questions drew on the emerging themes from the illness diaries and interviews, and were tailored to the situation in each PCO, but in general addressed:

- Awareness of the local service, and experiences with previous and new service configurations and attitudes to specific innovations within their PCO (e.g. the appointment of a respiratory GPwSI, the development of a managed care service, the development of a pulmonary rehabilitation service or a 'Hospital at Home' service).

- Workforce issues including preferences for who should deliver care, and attitudes to substitution of traditional providers e.g. substitution of a specialist nurse in a 'Hospital at Home' scheme as an alternative to acute admission, referral to a respiratory GPwSI rather than a respiratory consultant.

- Patient needs, expectations and visions for future development and the participants' wish, or not, to be involved in the development process.

4.4.4 Data analysis

After familiarisation with the data through listening to the recordings of the interviews and focus group discussions, the transcribed interviews were entered into NVivo 7 (QSR International. Doncaster, Australia) and coded into six broad themes. The illness diaries were carefully read and salient pieces of text highlighted along emerging themes. The illness diary, telephone interview and focus group data were analysed using the 'framework approach' which was developed specifically for applied qualitative research (Pope et al, 1999). This approach allows the combination of inductive coding (allowing understanding to emerge from close studying of the transcripts and the issues that emerge from respondents' accounts), and deductive coding (starting from the study objectives and thus shaped by specific information requirements). In the process of exploring and discovering the data and through regular meetings and discussions with the research team members, new themes and sub-themes developed (Appendix 8). In the discussions of the themes, we drew on policy documents and social science literature to inform our analysis and thinking. The analysis was carried out by one researcher with discussion regarding emerging frameworks and coding strategies taking place at regular intervals with other members of the team.

4.5 Phase IV: Multidisciplinary national workshop

Towards the end of the study, we approached selected healthcare professionals or managers leading change in other disease areas and from a wider group of PCOs, to enable us to explore the generalisability of specific themes emerging from the case studies. We offered the option of a semi-structured interview or attendance at the workshop. In the event all our potential supplementary interviewees attended the workshop.

We convened a national workshop with 30 participants recruited from the four case study PCOs as well as a range of national level stakeholders (policy-makers, healthcare managers, primary and secondary care professionals, representatives of patient organisations, researchers and educationalists).   Participants were selected to represent a range of perspectives on the key themes identified by the case studies. The co-applicants and study collaborators were personally involved in this workshop.

Feedback was provided on the emerging themes identified and the issues raised by the case studies.

We presented the findings from our study and preliminary conclusions to the participants. The briefing documents are given in Appendix 9.   Four multidisciplinary break-out groups were asked to focus on specific emerging themes (Policy and practice, Commissioning and clans, Patients and citizens, Roles and training) related to the study objectives.

We had two key aims:

- o To invite comment in order to validate, challenge and refine our findings and conclusions.   For representatives of the case studies this enabled them to comment on the accuracy of our account of their 'story'.   Other participants were asked about resonance with their specialist perspectives.

- o To assist with formulation of the broader implications, and with extrapolation (if appropriate) to other long–term conditions.

4.5.1 Data analysis

The researchers listened to the recordings of the group discussion which they had led and, supplemented by their notes and flip chart records compiled a summary of the important points.   We used these to validate our findings from the study, extend our conclusions, and understand the implications.

5 Phase I. Screening interviews

5.1 Summary

Participants

We undertook semi-structured telephone interviews with the person responsible for driving the reconfiguration of respiratory services in 30 PCOs during February to June 2006.

Key themes

For many PCOs the barriers of financial deficit, organisational uncertainty, disengaged clinicians, and contradictory policies presented insurmountable barriers to the effective development of sustainable services.

Those PCOs able to overcome the challenges of organisational fluidity and financial constraints in order to design and implement new services for people with long-term respiratory disease, largely directed these services at reducing admissions amongst the small number of people with complex needs.

Teamwork which actively involved primary and secondary care clinicians with PCO management seemed to be associated with broader service provision.

5.2 Participants

We contacted 110 English and Welsh PCOs between February and June 2006 with an invitation to participate in the study. Forty responded to our initial approach and agreed to consider our request. After discussion with colleagues and/or gaining permission from line managers, 30 identified a suitable person willing and able to be interviewed. The demographic details, merger and financial status of the PCOs, and the professional role of the interviewees are summarised in Table 5. Our interviewees were all PCO managers, with diverse job descriptions, with the exception of three PCOs which nominated their (potential or existing) GPwSI.

5.2.1 Models of care

Within the 30 sampled PCOs, we identified a range of respiratory service models, some including a combination of approaches and incorporating multidisciplinary teams. We reached saturation in terms of the service models identified. Details of the services under development in each PCO are given in table 5. In summary:
- Nine specifically involved GPs, either as GPwSIs or as less formal arrangements with 'interested GPs' or 'practice leads'. Six had, were developing, or considering formal respiratory GPwSI services.
- Sixteen had, or were developing, a role for community matrons
- Fifteen were nurse-led models, and a further seven included nurses in multi-disciplinary respiratory teams
- Three were developing models incorporating consultants working in the community
- Two PCOs were not prioritising respiratory care.

Table 5.   The PCOs: their demography of models of care, and role of interviewees

PCO	Population (to nearest 50,000)	Deprivation, Any special features	Financial status	Role of interviewee	Model of respiratory care
1	250,000. Urban,	Some areas of deprivation	In deficit	Manager (Nursing)	Respiratory specialist nurses Community matrons GPwSI referral service
2	200,000. Rural/coastal,	Some areas of deprivation, Elderly population	Unknown	Manager (Service development)	Community matrons
3	150,000. Urban,	Some areas of deprivation	In balance	Commissioner	GPwSI, respiratory specialist nurse Hospital specialist respiratory nurses Community matrons
4	150,000. Urban,	Some areas of deprivation	In deficit	Manager (Governance)	Respiratory specialist nurses Hospital trust respiratory nurses
5	150,000. Urban/rural,	Mostly affluent	In deficit	Manager (Service development)	No respiratory service
6	300,000. Small city,	Some areas of deprivation	In balance	Commissioner	Respiratory specialist nurses
7	100,000. Urban/rural/remote,	Mostly affluent	In balance	Manager (Nursing)	Respiratory specialist nurses Community matrons
8	150,000. Urban/rural,	Mostly affluent	In deficit	Manager (Service development)	Respiratory specialist nurses Interested GP
9	200,000. Urban/rural,	Some areas of deprivation	In deficit	Manager (Service development)	Hospital specialist respiratory nurses Pulmonary rehabilitation, Practice leads
10	200,000. Inner city,	High levels of deprivation	Unknown	Manager (Nursing)	Respiratory specialist nurses Community matrons Pulmonary rehabilitation

PCO	Population (to nearest 50,000)	Deprivation, Any special features	Financial status	Role of interviewee	Model of respiratory care
11	200,000. Urban/rural/remote,	Some areas of deprivation	Unknown	Manager (Service development)	Respiratory specialist nurses Practice leads
12	150,000. Rural,	Some areas of deprivation	In deficit	Manager (Service development)	Hospital respiratory specialist nurses and community consultant Pulmonary rehabilitation
13	250,000. Urban,	Some areas of deprivation	In balance	Commissioner	Hospital respiratory nurses Urgent care centre with community consultant
14	100,000. Urban/rural,	Relatively affluent	In deficit	Respiratory GPwSI	GPwSI and respiratory specialist nurse
15	200,000. Rural,	Some areas of deprivation	In deficit	Manager (Service development)	Respiratory specialist nurses Physiotherapist, Community matrons, Nurse educator in primary care
16	150,000. Urban/rural,	Some areas of deprivation	In deficit	Respiratory GPwSI (not in post)	Respiratory specialist nurses Potential GPwSI
17	300,000. Rural/coastal,	Some areas of deprivation, Elderly population	In deficit	Respiratory GPwSI	GPwSI, Respiratory specialist nurses, Physiotherapist Nurse educator in primary care
18	150,000. Urban/rural,	Some areas of deprivation	In balance	Commissioner	Respiratory specialist nurses Community matrons
19	200,000. Urban/rural,	Relatively affluent	In deficit	Manager (Service development)	Hospital respiratory nurses, Pulmonary rehabilitation
20	150,600. Rural/remote,	High levels of deprivation, Ex-mining community	In deficit	Manager (Nursing)	Respiratory specialist nurse

PCO	Population (to nearest 50,000)	Deprivation, Any special features	Financial status	Role of interviewee	Model of respiratory care
21	100,000. Inner city,	High levels of deprivation	In balance	Manager (Service development)	Respiratory specialist nurses Community Matrons, Pulmonary rehabilitation, Consultant and nurse support for primary care
22	250,000. Inner city,	Some areas of deprivation	In balance	Manager (Service development)	Hospital trust respiratory nurses Consultant outreach clinics Pulmonary rehabilitation
23	200,000. Suburban,	Mixed affluence/deprivation	In balance	Manager (Nursing)	Respiratory specialist nurses Telemedicine
24	110,000. Urban.	Mixed affluence/deprivation	In balance	Manager (Nursing)	Respiratory specialist nurse and physiotherapist Community matrons
25	300,000. Rural,	Some areas of deprivation	In deficit	Commissioner	Respiratory specialist nurse and physiotherapist, Community matrons
26	100,000. Rural,	High levels of deprivation, Ex-mining community	In balance	Manager (Nursing)	Community matrons
27	100,000. Rural,	Mostly affluent, Elderly population	In balance	Manager (Service development)	Up-skilling primary care Pulmonary rehabilitation
28	150,000. Urban/rural,	Mixed affluence/deprivation	In deficit	Manager (Nursing and social services)	Hospital trust respiratory nurses
29	150,000. Urban/coastal,	High levels of deprivation, Ex-mining community	In balance	Manager (Service development)	Hospital trust respiratory nurses Physiotherapist Consultant outreach clinics
30	250,000. Urban,	High levels of deprivation	In deficit	Commissioner	Hospital trust respiratory nurses Pulmonary rehabilitation GPwSI

5.3 Change and model development

Throughout the interviews, the impact of change emerged as an important theme which, in many cases, was discussed in a positive/negative dichotomy, both driving and impeding development. Reconfiguration of respiratory services was described within the context of the changing environment of the NHS in England and Wales as, at the time of the interviews, many of the Primary Care Organisations (PCOs) were expecting to merge and/or undergo structural reorganisation. Change impacted on all stages of respiratory service development from the initial drivers through the design phase to the implementation. We identified three phases of change and model development (summarised in figure 5): i) drivers for change; ii) designing new models of care; and iii) implementing change.

There was considerable overlap between these phases with some key factors impacting strongly at all three levels. For example: the need to achieve financial balance not only drove respiratory development (in order to reduce costly hospital admissions), but also influenced service design (favouring 'cheaper' models) and affected implementation (limiting innovations to short-term 'pilot' studies).

Figure 5. Summary of the phases of change and model development

Phases of change and model development Many of these themes were discussed in a positive/negative dichotomy, both driving and impeding development		
Phase Drivers for change	Designing new models of care	Implementing change

Themes Central policy
Local need
Financial balance
	Financial restrictions
	Teamwork
	Professional interests
	Patient perspective
	Previous experience
	Uncertainty due to
	  PCO reorganisation
	Policy and central
	  advice
		Financial restrictions
		Competing policies
		Opposition from
		  professionals

5.3.1 Drivers for change

Central policy

Many interviewees described the primary drivers to redevelopment as being central policies, particularly on shifting care into the community, proactive management of LTCs including the 'Expert patient' programmes, and broadening of professional roles. The impending PCO mergers and commissioner-provider split provided a fluid and uncertain context for these changes.

> *"Well I think it's to sort of deliver the sort of key areas around moving services out of hospital into the community where that's appropriate to do so. So we're trying to sort of reduce inappropriate hospital admissions and make sure the pathways are appropriate so only patients that need to go to hospital go to hospital."* [PCO 15: Respiratory nurse service, Interviewee: Service development manager]

> *"So as the PCO has become a much more commissioned PCO with different functions and much more business-like relationship with our provider, …. we are looking at community services and how they are doctored to avoid hospital admissions and meet some of the targets."* [PCO 25: Respiratory nurse service, Interviewee: Commissioner]

> *"…. again I think PCO initiatives seem to be driven from central government which, is understandable to a certain extent but the nature is that it tends to, unless you're very different and you're very enthusiastic, you'll find that to implement any change is extremely difficult."* [PCO 14: GPwSI service, Interviewee: GPwSI]

Local need

Recognition that change was needed to enhance local patient care was another important driver. Several PCOs were investing time and money in exploring local need with scoping exercises, and audits of service use. Some PCOs valued the input of local practitioners as a means of gauging patient needs; though others were concerned that clinical perspectives might not always reflect those of patients.

> *"It's sad because you know, we may be faceless bureaucrats but we've been working, excuse the expression, 'our guts out' to improve services for patients and make a difference."* [PCO 8, respiratory nurse service, Interviewee: Service development manager]

> *"Actually I think we have a very lively input from patients, that we've made sure that the patient voice is at the centre of this. Our patients have said to us what is important for them and our service development group have made that a key priority."* [PCO 8: respiratory nurse service, Interviewee: Service development manager]

> *"…my own driving is really an interest in respiratory, because I feel that as a group of patients over the years, with the way that the primary care has gone, certainly we've had NSFs for coronary heart disease and diabetes, those who have respiratory problems have sort of been*

neglected to a sort of second division and I feel that that's particularly unfortunate given the huge amount of morbidity that's around with regards to respiratory disease." [PCO 14: GPwSI service, Interviewee: GPwSI]

Financial balance

The imperative to achieve financial balance was frequently cited as a driver for change. Budgetary and resource restrictions drove service redesign by imposing a need for cost saving alternatives to hospital admissions.

"Well the top priority, I am sure you are going to hear this everywhere, is financial, absolutely nothing to do with redesign, but that is the absolute top." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"Although current changes are said to be clinically led, the truth is they aren't. There's a significant gap between rhetoric and reality, which leaves clinicians exasperated, because their commitment to the well-being of their patients comes second to economic and political forces" [PCO 14: GPwSI service, Interviewee: GPwSI]

5.3.2 Designing new models of service

Financial restrictions

Almost all interviewees spoke of how financial restrictions impacted on the design of respiratory services. Models were often chosen because of their cost-saving potential. In some cases these were not the preferred models, however financial restrictions did not allow for more expensive (yet potentially better) models of care. Specifically, a GPwSI service was often rejected as being too expensive in relation to other options. Sometimes, the choice of model was dictated by the presence of a specific funding stream or sponsorship for a particular project (for example: charity funding to start up an asthma education project for parents, pharmaceutical company sponsorship for pulmonary rehabilitation, funding for initiatives to attract GPs to under-doctored areas used to support GPwSI training):

"… then we'll see what we can do about it. Either it will be through pots of money that people have got stashed away, it might be trust fund, it might be sponsorship etc. We haven't got quite there…money is always a barrier." [PCO 11: respiratory nurse service, Interviewee: Service development manager]

"Yeah, I think there's only obviously so much amount of development money and obviously the people that can show the better cost savings sometimes get the development funding for that." [PCO 5: no planned development, Interviewee: Service development manager]

"I actually managed to get some sponsorship from a drug company and as a result have actually employed a physiotherapist who is providing pulmonary rehab services on the east side of the city." [PCO 22: respiratory nurse and consultant outreach service, Interviewee: Service development manager]

Teamwork

Teamwork was an enabler of change and service redesign in those PCOs, which harnessed the expertise available in primary and/or secondary care. Although managers and primary and secondary care clinicians might have different visions, alignment of perspectives could enable change. Patient involvement, however, in the local development teams was the exception rather than the rule.

> *"...well I work, and am working at the moment closely with our lead consultant and our lead GP in [town] on modernising and developing alternative COPD services and I would like to say that I think that that has been instrumental in bringing about the kind of changes and changed service that we are now developing..."* [PCO 3: GPwSI-led team, Interviewee: Commissioner]

> *"That, the fact that people have been co-operative and, and they've taken a 'can do' approach with a positive attitude to it. And there's other areas I'm working in where we could have achieved the same but we just don't have the same, same sort of relationships and attitudes and we don't seem to conflict in the respiratory clinical reference group - we have different ideas but that doesn't end up as a conflict."* [PCO 6: respiratory nurse service, Interviewee: Commissioner]

> *"We worked as a team really, through the National Primary Care Development Team, that sort of gave us the funding to really start to, because it put me in post and so I was able to co-ordinate the services and we had a COPD Steering Group that was chaired by our head of modernisation and on that Steering Group was you know the whole full multi-disciplinary team for patients with respiratory illness. We have patients, we had consultants, we had respiratory nurses, dieticians, occupational therapist, we had the discharge co-ordinator, there was the ambulance [service], there was the Social Services. So, there wasn't one particular individual. We worked as a team to deal with that."* [PCO 9: respiratory nursing team, Interviewee: Service development manager]

Professional interests

The presence of professional support or opposition was highlighted as an important factor influencing choice of model redesign. Some interviewees described how clinicians from primary or secondary care could actively 'champion' preferred models or conversely how opposition (for example, from consultants) could mean that certain choices were avoided. Some PCOs cited examples where the narrow perspective of a professional had restricted the possibilities of developing new ways of working, and the PCO had subsequently adopted strategies to counterbalance vested interests. More practically, availability of an individual with professional expertise and interest could determine whether a GPwSI or specialist nurse service was selected.

> *"And fantastically the consultants, you know, they send me articles they see in Thorax...I got sent one about GPwSIs the other day, and it's the first time that a consultant has actually come and said, 'Actually d'you*

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know, there might be a role for a GPwSI somewhere in this'. I practically fell off my chair." [PCO 6: respiratory nurse service, Interviewee: Commissioner]

"[The GPs] solution to service re-design was to go 'Well we're going to have a GP with a Special Interest, that's the solution because, you know, that's the way I look at life, that obviously is the solution because GPs and primary care are the way forward'. So he designed the response to the question based on his one fixed view, now it ended up being a more expensive [service] than was currently there and it didn't actually, it wasn't based on patient need and it wasn't using the skill mix that was available so it was quite an interesting learning experience for our local PEC [Professional Executive Committee: Clinical committees of PCOs which have, amongst other duties, responsibility for setting practice indicative budgets].*"* [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

"Nobody's come forward and expressed an explicit interest in becoming a GP with a Special Interest and so it hasn't featured in the model. However, the model is quite open to different ways of working so if that was to happen then it would fit nicely...." [PCO 23: Respiratory nurse team. Interviewee: Nursing manager]

Patient perspective

Patient views on existing services and proposed redesign were actively sought by some PCOs, usually in the form of satisfaction surveys, though a few were commissioning interviews and focus groups to help them understand the patients' perspective. Local groups also provided opportunities to identify patient perspectives.

"We're doing a full review of unscheduled care services at the moment so we're looking at all of that. And understanding what sort of deal patients get in an urgent or emergency situation, so that's being independently evaluated by [local university]." [PCO 26: Community matrons. Interviewee: Nursing manager]

"We have a Breathe Easy group which is a support group for people who have COPD but it's also a way that we talk about service development with them so that's ongoing." [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

Previous experience

Decisions about models of care were influenced, both positively and negatively, by previous experience. This could be the personal experience of a person involved in redesign, or the PCO may have had success (or otherwise) with specific models in other long-term condition areas.

"...having led on GPwSIs in orthopaedics and dermatology I personally understood the processes needed to put a GPwSI in place and therefore it didn't seem a huge problem to set it up, I felt as though I was quite

familiar with what we needed to do." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"Yes, yes I mean we wouldn't rule out the GPwSI model but I think what we have found with experience from elsewhere about the cost of the GPwSI service actually sometimes they work out more expensive than appointing a consultant." [PCO 19: Respiratory nurse service, Interviewee: Service development manager]

Uncertainty due to PCO reorganisation

Many interviewees commented that the chaos and uncertainty associated with the imminent PCO reorganisation acted as a major block to effective development. Uncertainty and lack of job security within PCOs due to the impending reorganisation caused the planning process to stall. Our interviewees described examples of staff demoralised as plans just reaching fruition were put on hold, existing services were threatened and managerial positions remained vacant pending new (but as yet undefined) structures. By contrast, however, several interviewees spoke positively of the potential for expanding their successful respiratory services to their future partner PCOs, or optimistically described opportunities to develop a new service.

"I suppose it's not impossible that the reorganisation of the PCOs could be a great opportunity, in the sense that it's a new start with a new, newly formed organisation." [PCO 7: respiratory nursing service, Interviewee: Nursing manager]

"...there's a lot of worried people. Because even though we have experienced change time and again, we've been around long enough, it's never been quite like this." [PCO 28: respiratory nurse service, Interviewee: Nursing manager]

"...because really what we've done in lots of the long term conditions is done sort of mapping work to see what our patient flows are and where we can improve things etc. and in a sense we've going to have to revisit a lot of that work with the reconfiguration, which means that I think some of the things we're trying to implement or some of the strategies we're trying to develop are going to be on hold at least until the autumn until we know we've got all the key stakeholders again involved." [PCO 15: respiratory nursing service, Interviewee: Service development manager]

"But I do think that maybe yes, having one PCO, there will be more strength there to sort of improve services. Because you'll be covering all of [area]. I think we probably have more commissioning power, so I suppose that's a positive side of it." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

Policy and central advice

Many interviewees commented that specific policies and frameworks had a major influence on their thinking, citing 'the NHS Plan', 'Care Closer to

Home' or 'LTC pyramid' in support of their plans for redesign, though they interpreted the advice in the context of their local situation.

"In terms of the current work, our focus of effort has been the Kaiser Triangle (LTC pyramid), has been looking at the top of the triangle for those most vulnerable patients. And putting locality systems in place, we don't have community matrons down here in [area], for several reasons. We had fairly well established intermediate care services and we felt that the community matrons would cause upset to our established intermediate care teams. And we've opted for a model of looking at locality leadership to ensure that patients who need case management are case managed by the most appropriate person to meet that individual's needs." [PCO 27: up-skilling existing primary care, Interviewee: Service development manager]

"Well, we've attempted to align our service redevelopment. For example, with COPD. Patients are designated as mild, moderate and severe and we've linked that to the triangle in that sense that these patients are self-managing, assisted care [or] case management. So we've attempted to use that framework as the basis for our service redesign." [PCO 8: respiratory nurse service, Interviewee: Service development manager]

5.3.3 Implementing change

Careful design and planning did not always ensure successful implementation. Policies such as Payment by Results (Department of Health, 2003b) could work against the service redesign, causing tension between the hospital trust and the PCO. In some cases, service design proceeded successfully only to have a key appointment or initiative stopped (sometimes very suddenly) due to lack of funding.

Interviewer: *"Okay and do you encounter any obstacles or barriers to introducing these changes?"*

Interviewee: *"Money."* [PCO 11: respiratory nurse service, Interviewee: Service development manager]

"I mean we had plans drawn up to fund myself and a respiratory nurse specialist in the community and this was going to be part of the local development plan but at the twelfth hour, the eleventh hour I should say, the PCO pulled the plug on it because they had no money, so I found out within sort of a week of this meant to have been going ahead that it wasn't going to go ahead, so we had no funds." [PCO 14: GPwSI service, Interviewee: GPwSI]

Some interviewees described how implementation of the newly designed changes could be impeded by reluctant members of the healthcare teams, perhaps perceiving the proposed changes as a threat. There was particular emphasis on the need to change the medical culture for the new models to be accepted.

"…so having set that up we are now looking at how we can develop it and take it a bit further but also just to get our GPs to make use of it is, you know…old habits die hard and they're used to referring to the hospital, you know, and we've got to try and turn them around. And the other big, big challenge is that the hospital consultants are very, very reluctant to send even follow up patients to our GPwSI and changing that culture is exceedingly difficult…." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"Well, we have had quite a lot of resistance from the respiratory team, I have to say, the manager, who will say to me: 'Oh yeah it's a great idea'. But then the matrons struggle to get a service running with the respiratory nurse, cause I think the respiratory nurse who's new is right in the middle of it all, between her manager and my matrons." [PCO 7: Community matron and respiratory nurse team, Interviewee: nursing manager]

"…[the consultant]'s happy about two out of the three things. He's happy with community based services to support patients when they're discharged because he can say 'I'm happy for you to go home, Mrs. Whatever. Off you go and you'll be liaising with the respiratory nurse'. He's happy about the idea of specialist nurses supporting generalists in optimising the care of a patient with COPD, so optimising their treatments, sorting out, you know, their pulmonary rehab all that kind of stuff. But when it comes to a patient having an acute exacerbation for example where they would currently go into hospital he's not very comfortable at all about that patient being managed in a primary or community care setting." [PCO 12: Hospital trust early discharge service, Interviewee: Service development manager]

5.4 Functions of the specialist services

All but two of the PCOs described clinical services developed to address the needs of people with respiratory (usually COPD) disease. The majority identified the need to develop a strategic approach to the provision of care for people with respiratory (and other long-term) conditions and to meet educational needs (especially in primary care), but relatively few described clearly defined plans for addressing these issues. Examples of clinical, educational and strategic roles described by interviewees are in Table 6.

Table 6.   Examples of specialist services described by the PCOs

Role	Examples
Clinical service provision	'Hospital at Home' services including early supported discharge
	Community matrons, some with respiratory training
	GPwSI referral service
	Community-based pulmonary rehabilitation
	Community-based consultant
	Palliative care services
	Urgent care centre and links with ambulance service
	Telemedicine
	Meteorological Office forecasting
	Community-based oxygen services
	Expert patient programme
Education and quality improvement	Spirometry training for practice nurses
	General COPD training for general practice, study days
	COPD management toolkit for the practices
	Respiratory training for community nurses
	Education, mentoring and support to primary care clinicians
	Specialist nurse facilitator
	Respiratory locally enhanced services
	Audit, feedback and training programme
Strategic planning	PCO-wide pathways and services
	Patient involvement in pathway development
	Integrated clinical and social care, community beds
	Local respiratory networks
	LTCs planning - addressing co-morbidity
	Liaison with respiratory teams in neighbouring PCOs

5.4.1 Clinical service provision

Almost exclusively, the clinical services described were designed to meet the needs of patients at the top of the LTC pyramid (see figure 1).

The priority for all the PCOs was the reduction in hospital bed-days, though the approach taken varied between localities. The most common model was a nurse-led intermediate care service, often complemented by community matrons providing case management for a few highly complex patients, although other professionals (e.g. physiotherapists, GPwSIs, community-based consultants) were included in some PCOs.

> *"Then we have our [respiratory] team which works with the more vulnerable patients and the revolving door patients and basically provides hospital-at-home and case management."* [PCO 17: GPwSI-led service, Interviewee: GPwSI]

Isolated examples of other approaches were given, including an 'urgent care centre', integrating care with social services, developing community hospitals, and working with other front-line staff such as ambulance

personnel. For local reasons, (e.g. low prevalence of COPD) two PCOs had not prioritised the provision of specialist COPD services.

> *"Urgent care, developing an urgent care centre...An alternative way, so a building that will provide an alternative method of treatment for those patients that may not require hospital admissions, so it could provide consultant access, rapid access to diagnostics, treatment and return home basically, that's one of the key priorities."* [PCO 13: urgent care centre, Interviewee: Commissioner]

Pulmonary rehabilitation was universally acknowledged as important, though few interviewees were satisfied with the service they provided. Most described their current service as *"inadequate"*, or *"a pilot project"* with an uncertain future, though hoped that in time they would be able to increase provision.

> *"And finally, when we actually get round to reviewing it, pulmonary rehabilitation has started but we want to do something really dramatic there...Well we've done a few pilots this year, they have been very successful but I think it's about establishing a service that runs continuously so that patients can get on it very quickly and can step on and step off. And also to run it in the community, in leisure centres so that it is much more accessible."* [PCO 23: Respiratory nurse team. Interviewee: Nursing manager]

> *"We started a community pulmonary rehab programme in addition to the one that the acute trust runs but the funding runs out for that at the end of March. So, at the moment, my responsibility is trying to ensure that we get the funding to continue that through Practice-Based Commissioning."* [PCO 9: Respiratory nurse team, Interviewee: PCO manager]

A few interviewees described initiatives to reduce out-patient referrals, either by employing a community-based consultant, or a GPwSI, or by using a referral management centre to triage referrals. Oxygen therapy was also mentioned by some PCOs as a service that could be developed in the community. Other clinical services described were isolated examples of innovative practice (e.g. tele-monitoring, Meteorological Office health forecasting, palliative care services for people with COPD). Services for respiratory conditions other than COPD or for children with respiratory disease were rarely mentioned.

> *"I think there's always been an aspiration that the team would move on from COPD as well, that COPD would be its main focus...then, as services are established and skills and expertise in that area generally across the health community kind of increased, that other respiratory diseases would kind of come into being such as asthma and so on, but again there are no definite plans for that to happen at this point in time."* [PCO 21: respiratory nurse and community matron team, Interviewee: Service development manager]

5.4.2 Education and quality improvement

The need to raise standards of respiratory management in primary care was widely acknowledged, though only a minority of PCOs had well developed plans in place for how this was to be achieved. Whilst some PCOs used audit tools and support strategies such as in-house mentoring to work with practices, others relied on educational methods known to be ineffective at changing practice (e.g. lectures, distributing local guidelines) (O'Brien et al, 2001). Existing initiatives, such as the Primary Care Collaborative (National Primary Care Development Trust, 2008) were seen as useful foundations on which to build. Plans for training nurses were often described in clearer terms than strategies to improve GP skills.

"What we try to do is, we work with a longer pathway. So we have for example, we work with practices and we send in, we have what we call our [specialist nurse], who's a nurse who basically just goes in and works with practices to set up systems of identification and better management…But she specifically works with primary care to develop services within primary care." [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"So the respiratory team have outlined, we have a CDM [Chronic Disease Management] monthly newsletter so it's gone out in the newsletter about what workup should happen for patients, what's expected so we've been really clear about that. What tests and blood tests etc. need to be done before they go to a clinic." [PCO 11: respiratory nurse service, Interviewee: Service development manager]

Some PCOs were developing a 'competency-based' approach to defining training needs, particularly in the context of community nursing, as district nurses, specialist respiratory nurses and community matrons all contributed to the care of people with COPD.

"I think, very much in terms of defining the care pathways very carefully. All the ones like mapping the service and then deciding who needs to fit in where within that mapping and then the competencies for each of those to be utilised and based on any kind of national competency framework." [PCO 4: respiratory specialist nurses, Interviewee: Governance manager]

5.4.3 Strategic planning

The LTC pyramid was widely cited, and for many PCOs was the basis of their strategic planning, though many acknowledged that, at the moment, their focus was primarily *"looking at the top of the triangle for those most vulnerable patients"* with less clarity about how to address the needs of the majority of patients at the lower levels of the pyramid. One approach was to develop patient pathways with a number of interviewees describing multidisciplinary groups working on PCO-wide pathways. Some PCOs had a respiratory strategy that was embedded *"in the context of the long term conditions agenda"*, potentially *"connecting up"* care for people with co-morbidity and dovetailing with Expert Patient programmes to *"help people*

take control of their own health" (Department of Health, 2001b). At one end of the spectrum there were PCOs with well-developed teams, often given a name and a clear identity, with a phased programme of development. By contrast, other PCOs were yet to develop a strategy.

> *"Our programme for long term conditions within this PCO is known collectively as [programme name] and in phase one of the programme we established a community respiratory service, a community rapid response service which was linked to intermediate care, the development of community matrons and the further expansion of community beds. So whilst they are all individual service developments they are all connected together really to deliver an overall impact, if you like, in terms of the development of services for improved management of people with long term conditions and particularly older people in that first phase."* [PCO 21: Respiratory nurses and community matrons, Interviewee: Service development manager]

Mindful of the impending reorganisation of PCOs, some trusts were already discussing with colleagues from neighbouring PCOs how their strategies might align in the event of a merger, potentially enhancing services and sustainability. For many others, however, uncertainty about the future structures, and their own personal role within the reorganised trusts, was expressed in terms of *"confusion", "frustration", "instability"* with a resultant sense of inertia making it *"very, very, very difficult to plan anything".* Financial restrictions, often linked with the reorganisation, were a major factor impeding development.

5.5 Teamwork and the functions of specialist service

Figure 6 illustrates an observed association between increasing teamwork including primary and secondary care clinicians with PCO management, and a broader approach to clinical, educational and strategic aspects of respiratory service development.

Figure 6. Association between increasing engagement of key stakeholders (PCO manager, primary and secondary care clinicians) and the breadth of the specialist roles described (clinical, strategic and educational)

		PCO	2ary	1ary		Clinical	Strategic	Education
No clinical involvement	2							
	5							
	18							
	20							
Either primary or secondary care clinical involvement	26							
	6							
	7							
	21							
	22							
	25							
	28							
	29							
	1							
	16							
Some involvement of both primary and secondary care	12							
	13							
	23							
	24							
	30							
	3							
	9							
	10							
Active involvement of both primary and secondary care	4							
	8							
	11							
	14							
	15							
	17							
	19							
	27							

Involvement of PCO managers, secondary and primary care clinicians are illustrated in the first three columns; the depth of shading reflects the degree of engagement. (see table 1 for details of grading)

☐ No involvement
◻ Limited engagement
▨ Substantial engagement

Roles provided by the specialist service are illustrated in the second three columns; the depth of shading reflects the priority, and depth of the service provided

☐ No provision
◻ Role mentioned, but with minimal corroborative evidence
▨ Role described, with some specific examples
■ High priority given to role

5.6 Teamwork

Teamwork between managers and representatives from primary and secondary sectors emerged as a key factor in the effective development of services with stakeholders perceived as offering diverse perspectives and complementary different skills. Some interviewees offered enthusiastic descriptions of coherent teams driving change.

> *"What was very unique about our project team was the fact that we had clinicians and managers working very closely together across primary, secondary care. And I think that established the right team structure to actually get things done."* [PCO 17: GPwSI-led service, Interviewee: GPwSI]

Teamwork, however, did not guarantee success as financial, political and organisational considerations *"got in the way of otherwise robust plans"*. Constant frustration not only blocked development, but undermined the team.

> *"But there's so much goodwill, where managers and clinicians are working together to make a difference for patients and so much of that goodwill is squandered when it's not followed through. That so much money is wasted from plans that never come to fruition. And we shouldn't embark on a journey if we're not going to see it through to the end."* [PCO 8: respiratory nurse service, Interviewee: Service development manager]

PCO managers were seen as having an important facilitatory role, often providing an essential drive *"at the start of the programme"* by focusing attention on the need to develop pathways to prevent 'inappropriate' admissions. The majority of PCOs turned naturally to the acute sector for their clinical advice in setting up 'Hospital at Home' services, especially in the absence of interest from GPs. Lack of 'buy-in' from GPs was cited as a significant threat to implementation of services.

> *"Yes and there is a bit of a change I suppose within the PCO about, well there's no point in us doing this if this isn't going to be owned by the practices, you know. It needs to come from them really now, every service development now really should have the support of the practices behind it."* [PCO 21: Respiratory nurses and community matrons, Interviewee: Service development manager]

Tensions could arise between the PCO managements' need to achieve financial savings and the clinicians' broader vision of improved services. Relationships between primary and secondary care, or between respiratory nurse specialists and community matrons, were sometimes fraught. Candid discussion between all stakeholders could allow diverse perspectives to be appreciated and objectives aligned.

> *"I think the PCO driving force is the economic side of things … so I do feel that I'm basically trying to drive through a clinical area but obviously*

understand that you will only achieve these things if you satisfy other people's aims as well " [PCO 14: GPwSI service, Interviewee: GPwSI]

Clinical leaders from primary or secondary care sometimes fulfilled the role of champions, being described as *"very, very committed to developing the service"* and people who *"have a passion to move things on"*. It was thought that to be effective, clinical leaders should be knowledgeable, visionary, enthusiastic and tenacious, locally respected clinicians who were good at building relationships, and who were supportive mentors who could set standards.

If natural leaders were not forthcoming, PCOs often sought ways to encourage clinical engagement, for example by obtaining a *"specific nominated lead in each GP practice for respiratory disease"*. PBC was widely seen as a potential mechanism for increased involvement of clinicians.

> *"I mean we see it [PBC] as the real drive to get them much more in a leadership position to say well, you know, this isn't right, how can we provide it differently so I would say, you know, we anticipate it having a huge impact on influencing where resources are going and their referral patterns etc."* [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

By contrast, entrenched professional attitudes (variously described as *"obstinate", "resistant", "territorial", "prejudiced"*) could block effective engagement of clinicians, though (more generously) were also described as *"a lack of understanding"* which might respond to *"an evolutionary approach"*.

5.7 Professional boundaries

The challenge

A number of interviewees described considerable opposition from existing professional groups to the reconfiguration of services and recognised that these attitudes were underpinned by a range of perceptions and motives. These included a perceived threat to current status, role or income, and a reluctance to change long-established practices, but also a lack of understanding of the potential of other sectors combined with a genuine concern for patient safety.

> *"Correct, it's a little bit about protectionism and a little bit about he loses control and a little bit about, actually does the evidence base support that these services can be developed safely, to be safe and indeed effective."* [PCO 12: respiratory nurse team, Interviewee: Service development manager]

> *"Barriers I suppose…sometimes there can be tension you know from people not wanting to necessarily let go of something they've always done, and I suppose a good example would be you know from an acute perspective if you are a clinician working in the acute sector letting something go that could quite easily be done in a community setting and*

being averse to that kind of change." [PCO 19: Respiratory nurse service, Interviewee: Service development manager]

"I think also this idea that the acute sector needs to be in control of it all but again do they really understand what it's like to live in the community so I know our lead nurse has had quite a few challenges in trying to get people to realise you need to start from a different perspective if you are going to have a prevention model rather than a reaction model." [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

"No I don't think it's being obstinate I mean don't get me wrong there are probably some individuals who are obstinate I think you'll find that in all walks of life...I think generally it's about understanding and, you know, what the ability of community and primary care can do." [PCO 19: Respiratory nurse service, Interviewee: Service development manager]

Attitudes held by powerful professional bodies (examples were provided from primary and secondary care, and nursing services) were at times described in confrontational terms and clearly posed significant threats to plans.

"You want to do something and unless you've got a very experienced, say GPwSI, the consultants can just say 'No, we won't endorse this, we won't give clinical supervision, we won't support it, we're not responsible, you know, so we won't play the game' and it is, you have to be very strong minded and determined to break down some of those things." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"There were also problems around the new proposed consultant, who would employ that consultant. And the PCO felt strongly that it should be a PCO-employed consultant and again we came up against opposition from the hospital physicians that it wouldn't be a viable post: 'No consultant physician in their right mind would take up a PCO based and employed contract because they would lose out on the access to acute services, access to ICU [Intensive Care Unit], training and development, etc' and that none of them would consider working with a PCO contract basically, so there was a big divide there." [PCO 13: urgent care centre, Interviewee: Commissioner]

"My matrons are more than capable of doing a comprehensive oxygen assessment on their patients. But there's a battle going on between them and the respiratory team who's saying 'But you shouldn't be doing them at all'. So why would I, [send] my matron in there and [have] another qualified nurse going in there as well, when my matron is more than capable [of doing] oxygen assessment?" [PCO 7: respiratory nursing service, Interviewee: Nursing manager]

Addressing the challenge

Although some interviewees talked in terms of conflict, in general, negotiation was the preferred approach to resolving problems, with a focus

on facilitating understanding between different perspectives and enabling consensus.

> *"I think by having kind of multi-professional groups to look at these kinds of issues, but to break down some of those barriers because then, you know, both primary and secondary care have a much better understanding of what each other can do, and what they, you know and what they should be doing or not."* [PCO 19: Respiratory nurse service, Interviewee: Service development manager]

> *"My personal style, which has been a slight source of frustration to some of the directors, has been to get a high degree of consensus…And if you force integration you end up with disintegration."* [PCO 27: up-skilling existing primary care, Interviewee: Service development manager]

> *"I mean we have had fairly huge battles trying to get the acute sector to realise that actually it's not about them driving this. It has to come from the community if we are going to make a difference."* [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

At times more subtle strategies were required, such as flattery (*"we value you as a clinical leader in this health economy and we want you to take a leadership role…"*) or avoiding confrontational terminology (*"we might not call it GPwSI we might call it something else but essentially that would be what it would be"*).

> *"I think it will be an evolutionary process, that's just my own perspective. I mean we could do it more in a big bang, but I think we, because of that respiratory consultant, and we've only got the one, I just don't think it's the way to go."* [PCO 12: respiratory nurse team, Interviewee: Service development manager]

5.8 Practice-based commissioning

PBC was generally welcomed as offering potential for primary care clinicians (usually GPs, though nurses were sometimes included) to use their knowledge of current issues to *"commission some of the services they actually need"* and *"set the direction"* for service provision.

> *"And we feel if the practice based commissioners are strong in defining, along with public health, the true needs of the local population, we will then need to engage clinically, and I think this is the main direction which is a change from the past. Clinically led and clinically championed, as different from numbers and organisationally led by managers within commissioning. And that's been a gap. The clinical input and the clinical, not just engagement, but not just advice, but making sure it does happen. That level of clinical involvement has been a deficiency for commissioning and we want to address that ASAP [as soon as possible], within reconfigured status, but utilising Practice-Based Commissioning as the foundation for it."* [PCO 4: respiratory specialist nurses, Interviewee: Governance manager]

Some PCOs were looking to clinicians for innovative ideas and new approaches to problems, and predicted that some practices would develop 'special interests' and become leaders in specific areas. Opinions were divided about whether this would raise standards that could *"spread to other practices within their locality"* or whether this would increase inequity as other (often more deprived) communities within a PCO would be left behind.

"We're trying to engage Practice-Based Commissioning Consortia around well actually 'how do we do the thing differently', so that's the framework that we're trying to use to, well, generate more ideas than we can generate at the PCO HQ." [PCO 12: Hospital trust early discharge service, Interviewee: Service development manager]

"You know, what is coming out of Practice-Based Commissioning Consortia, you know, you've got ten practices you will inevitably have some that have more of an interest, more capacity, more capability around any, you know, one particular area and, you know, this is the case with respiratory services...and I suspect they will be more or less by definition the leaders of that spread to other practices within their locality." [PCO 12: Hospital trust early discharge service, Interviewee: Service development manager]

"There are some concerns, though, for the city in terms of Practice-Based Commissioning in that, whilst choice and flexibility of different models of care is fantastic, at the moment we have got health inequalities widening and our concern at the moment is, we suddenly let those that are really interested just go off on their own, what they'll do, because they are actually the more affluent part of the city, we will probably see the health inequalities get even worse. So there are concerns from a public health perspective about Practice-Based Commissioning .... We need to give differential support to those areas specifically where there is greater health inequalities." [PCO 30, GPwSI, Interviewee: Commissioner]

Some interviewees doubted whether GPs, as providers, fully appreciated the implications of the move to commissioning, or questioned their understanding of the broader context of how national priorities and targets could determine service priorities. Others, more cynically, saw an opportunity to use the financial inducements of PBC to engage GPs in improving services.

"What is tending to happen in Practice-Based Commissioning clusters is we're still using the old thinking of provider led. So most people who are going to Practice-Based Commissioning clusters think it's about what services can we provide in primary care rather than what services should we commission in primary care. And then actually look at who is going to be the best provider." [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"I think the people actually working on developing the services may not fully grasp the issues and the impact of potential consequences. And I

think it needs to be really sensitively handled and people need to work in a really open, honest way and have common goals and be willing to try new ideas. People aren't used to marketing their services either. It should improve care, I would have thought, hopefully, it will be a testing time." [PCO 23: Respiratory nurse team. Interviewee: Nursing manager]

"GPs are very motivated by money aren't they? So Practice-Based Commissioning and its financial rewards is motivating the GPs in our area and I suppose I'm kind of taking advantage of that lever because it's making patients get improvements." [PCO 27: upskilling existing primary care, Interviewee: Service development manager]

5.9 Conclusions

In response to policy directives, PCOs were developing a range of services to meet the needs of people with long-term respiratory disease, most commonly focused on reducing admissions amongst those complex needs. Broader service provision, encompassing a strategic approach to care at all levels of the LTC pyramid, was associated with successful teamwork, involving both primary and secondary care clinicians with PCO management.

Contextual issues, which challenged effective development of sustainable services, included the uncertainty of major organisational change, the need to achieve financial balance and the tension created by contradictory policies. Disengaged clinicians, fraught relationships, and entrenched professional attitudes could block proposed developments, unless the different perspectives were aligned. In-depth exploration of these issues was a priority for the case study phase.

6 Phase II. Case studies

6.1 Summary

The four case studies

The screening interviews (presented in Chapter 5) provide a picture at one point in time of arrangements of care in 30 PCOs, together with some of the main obstacles and facilitating factors in service development. The case studies complement these data by capturing in-depth the organisational dynamics which shaped service developments and the associated workforce reconfiguration over one year spanning 2006 to 2007.

Impact of change and contextual factors

The substantial changes following reorganisation to reduce the number of PCOs and strengthen their commissioning function, could offer new opportunities for service reconfiguration and workforce change. The changes could also have a disruptive effect, with managers and clinicians preoccupied with reorganisation and job losses in their own and neighbouring organisations and unable to plan services beyond the short-term, because of uncertainty about the future context.

The new roles which developed from service reconfiguration were dependent on a range of factors including: the presence of individuals with an interest in developing respiratory care; their access to national networks; PCO conditions (e.g. merger, financial status, commissioning structures); and the interests of hospital trusts. Financial considerations appeared to be a major driver determining service development and commissioning priorities.

Commissioning and functions of the services

In common with the finding from the screening interviews, although some respiratory services in the case study PCOs were able to provide more comprehensive care, commissioned services tended to concentrate on the provision of intermediate clinical care and on the needs of patients at the top of the LTC pyramid. Education and training, initiatives aimed at longer–term prevention (e.g. pulmonary rehabilitation) and strategic planning tended to be squeezed out when resources were scarce.

Implementation of the new structures and processes for commissioning (e.g. the commissioner-provider split within PCOs introduced in October 2006) was at an early stage in three of the case studies and many managers and clinicians were confused about the developments. The structures and processes for PBC were even less well-developed, but some interviewees were enthusiastic about the potential benefits PBC might bring once it had been fully implemented. The prospect of competition from private providers was beginning to have an impact on service development.

Importance of professional boundaries, relationships and networks

Unsurprisingly, professional boundary work was a key factor shaping service development in all four case studies. The extent to which individuals and groups contested territory was a key determinant of the shape and effective implementation of new services. Where it was possible to align interests and bring benefits for all parties, new services were able to develop; conversely, where new services were perceived to threaten existing professional interests without providing compensating factors, they were strongly resisted and development stalled.

Personal relationships based on collegiality, past history and common professional interests could reduce the impact of these deep-rooted professional boundaries allowing individuals (e.g. GPwSIs and specialist nurses) to be accepted by their peers as able to extend their previous roles and to work in new ways.

Personal relationships were also instrumental in enabling individual clinicians with an interest in developing respiratory services to make contact with like-minded local clinicians and managers. This could allow service development to continue at times of rapid change during which familiar arrangements were sometimes being dismantled in advance of new and transparent structures and processes being put in place.

Team-building, by developing personal relationships, could mitigate some of the adverse effects of the long-standing unhelpful professional boundaries, but effectiveness was dependent on a range of factors including the make up of the team, the personalities of individuals (particularly the team leader(s)) and the resources available to support the team (e.g. time and training).

Access to networks based on common professional interests was important for professionals entering new specialised roles. These networks provided support, advice and information. GPwSIs' networks were closer to centres of decision-making within their organisations than those of specialist nurses. GPwSIs also had access to national networks, which supported their role through information, advice, contacts and political lobbying.

6.2 Presentation of findings

6.2.1 Anonymity

We refer to the four case studies using the following descriptors to maintain anonymity and aid interpretation:

- Team PCO

- Merged PCO (formed by the merger of County Town PCO with Coastal, Small town, Affluent and Central PCOs)

- Commissioning PCO

- Rural PCO.

To assist in preserving confidentiality, some of the local details have been disguised.   All names used are pseudonyms.

6.2.2 Conventions

We encountered many different names and titles, especially for nursing and PCO managerial roles. For clarity, and to preserve anonymity, as some of the titles were specific to individual PCOs, we have adopted the conventions described in Table 7.

Table 7.   Descriptors used in the report

Sector	Role(s)	Descriptor
PCOs	All managerial roles in the PCO, regardless of their official title	PCO managers
	Roles which are exclusively commissioning	Commissioners
General Practice	General Practitioners	GPs
	Practice nurses providing respiratory care within their own practice	Practice respiratory nurse
	GPs with a PCO role, even if they are not formally accredited as a GPwSI	GPwSI
Community	Nurses providing specialist respiratory services in the community (even if they are employed by the hospital trust)	Community specialist respiratory nurse
	Nurses with a remit to provide case management for people with complex needs	Community matron
	Nurses with specialist respiratory training and a remit to provide case management for respiratory patients with complex needs	Respiratory community matrons
	Respiratory consultant paid by the PCO to provide respiratory care in the community	Community respiratory consultant
	Non-nursing qualified provider of supportive clinical services	Healthcare assistant
Hospital	Consultant respiratory physicians employed by, and working within a hospital	Respiratory consultant
	Nurses providing specialist respiratory services employed by and working (predominantly) within in the hospital	Hospital specialist respiratory nurse
	All hospital managers regardless of title	Hospital manager

6.3 Structure of the case study results

Case-by-case data

For each case study PCO we present the data under the following headings:

1. *The service setting:* An overview of the size, demography and geography of each organisation, their current (re)configuration status, and their primary and secondary care service provision.

2. *The story of reconfiguration of respiratory services:* A chronological overview of the development of the service model in each area is followed by a fuller description of events.

3. K*ey features of development of the local respiratory service in each setting.* This analyses how the local reconfiguration was experienced by respondents involved in service development, and how negotiation and contest about professional territories and boundaries impacted on

service development. The impact of change and the local structures of commissioning are described to create an understanding of the constraints and opportunities which shaped local players' engagement in service developments and the reconfiguration of new specialist roles.

4. *Summary: The key themes.* Each case study concludes with a summary of key points relating to the three main analytical themes: change, professional boundaries and commissioning and markets.

Themes across cases

The final section (Section 6.10) presents the cross-case analysis of the three main themes (change; professional boundaries and commissioning; and markets), with reference to the literature (discussed in Section 2.6) as a basis for theoretical generalisation from our case study data.

6.4 Participants and interviews

Participants and interviews conducted during the year-long case studies are tabulated below. 'Initial' interviews were requested from all stakeholders who appeared from the screening interviews to be involved in, or affected by the respiratory service reconfiguration. Most were undertaken face-to-face during a site visit, though a few were scheduled by telephone for the convenience of participants. 'Mid-phase' interviews were undertaken with any additional participants identified as significant players during the initial data collection and also at intervals with key stakeholders to follow the unfolding story. We also specifically aimed to interview representatives of significant groups who appeared not to be involved with the reconfiguration process despite having a role in the care of people with LTCs (e.g. GPs in Commissioning and Rural PCOs; respiratory consultants serving Rural PCO). In Merged PCO, we interviewed representatives of the four trusts merging with County Town PCO about their pre-merger situation in order to understand the impact of reorganisation (Table 8). Exit interviews were conducted selectively with key informants to enable the situation at the end of the case study to be understood. Our intention had been to include an exit interview in each PCO with a key informant whom we had interviewed at the beginning of the case study. However, this proved not to be possible in two PCOs because our key informant changed roles during the year.

Table 8.   Table of case study interviews by stage of study

PCO	Interviewee	Initial phase	Mid phase	Exit
Team PCO	PCO manager 1	✓		
	PCO manager 2	✓	✓	✓
	GPwSI	✓	✓	
	Respiratory consultant	✓	✓	
	Community specialist respiratory nurse		✓	
	PCO manager 3		✓	
Merged PCO: County Town PCO	GPwSI 1	✓	✓	✓
	PCO manager 1	✓	✓✓	
	Community specialist respiratory nurse	✓	✓	
	GP PBC lead	✓	✓	✓
	Community matron	✓	✓	
	Hospital specialist respiratory nurses 1 & 2	✓	✓	
	Respiratory consultant	✓	✓	
Coastal PCO	GPwSI 2	✓	✓	
	Practice respiratory nurse 1	✓		
	Practice respiratory nurse 2	✓		
	PCO manager 2		✓	
	Respiratory consultant		✓	
Central and Affluent PCOs	Community specialist respiratory nurse	✓	✓	
	PCO manager 3		✓	
	PCO manager 4		✓	
	PCO manager 5			✓
Small Town PCO	GPwSI 3		✓	
	PCO manager 6		✓	
	Hospital specialist respiratory nurse			✓
Commissioning PCO	PCO manager 1	✓		
	Senior community specialist respiratory nurse	✓	✓	
	Paediatric specialist respiratory nurse	✓		
	Respiratory consultant 1	✓	✓	
	GP PBC lead 1	✓	✓	
	Hospital manager	✓		
	PCO manager 2	✓		
	Respiratory consultant 2	✓		
	GP PBC lead 2		✓	
	PCO manager 3			✓
Rural PCO	PCO manager 1	✓	✓	
	PCO manager 2	✓	✓	
	Community specialist respiratory nurse	✓	✓	
	PCO manager 3	✓	✓	
	GP 1		✓	
	GP 2		✓	
	GP 3		✓	
	Practice nurses		✓	
	GP 4		✓	
	GP 5		✓	
	Practice respiratory nurse		✓	
	GP 6 & GP 7		✓	
	Respiratory consultant 1			✓
	Respiratory consultant 2			✓
	PCO manager 4			✓

6.5 The four case studies

Table 9.   Key features of the four case studies

Team PCO	Merged PCO
GPwSI (in training) service.	Established GPwSI service.
Development driven by a local Team with a 'diagnosis to death' vision of respiratory services. The team actively involved GP, PCO and hospital interests.	Roll out of the established GPwSI referral service to the enlarged PCO. Development linked to a 'turnaround' team's stringent financial measures.
Commissioning PCO	**Rural PCO**
Nurse-led community respiratory service.	One specialist respiratory nurse supporting GP and community nurse care
Intermediate care service commissioned by PCO primarily to reduce hospital admissions.	Development was focused on using existing resources, with the appointment of a charity-funded second community specialist respiratory nurse

6.6 Team PCO

6.6.1 The service setting

Demography

Team PCO commissions care for 100,000 people living in one market town surrounded by smaller towns and rural areas. The population is fairly affluent, enjoying higher than average socio-economic status by UK standards. There are pockets of relative deprivation.

PCO reorganisation

The PCO did not merge, but established joint management structures with a neighbouring PCO, involving some disruption and change to management posts. There was no change in the financial situation, and the PCO had only a small deficit.

Organisation of respiratory care

The PCO relates to one hospital trust, which had just achieved Foundation Trust status. One of the three Trust hospitals is located within the PCO. The local respiratory consultant was appointed recently after the post had been vacant for two years

There are 11 GP practices, and one Walk-in Centre providing primary care services.

6.6.2 The story of reconfiguration of respiratory services

Table 10.   Chronological overview of key events in Team PCO

Date	Key developments
2004	The PCO Clinical Director approached an interested GP to be a respiratory clinical lead.
	Assisted by a PCO manager, a plan was developed for a GPwSI-led service and a respiratory specialist nurse.
	The plug was pulled (along with plans for community matrons) for financial reasons.
	Fortuitous contact from a national advocate of the GPwSI model, inviting the GPwSI to attend a weekend course for developing respiratory teams.
	The GPwSI, three PCO managers and the respiratory consultant attended the courses as a result of which the 'Inspire' team was born.
2005	The GPwSI started to work one session per week in the hospital respiratory outpatient department under supervision by the consultant.
	A respiratory plan was submitted as part of the Local Development Plan, based on a vision of an all-encompassing reconfigured COPD service that would provide care from *"diagnosis to death"*.
2006	At the last minute, promised funding was again withdrawn as part of a PCO-wide plan to reduce overspend. The GPwSI mobilised support from GP practices (the plan had the support of the PBC consortium) and one of the PCO managers challenged the Chief Executive.
	The funding application was accepted by the Professional Executive Committee with the proviso that it would be cost neutral by 1st April 2007.
	A community specialist respiratory nurse was appointed.

6.6.3 A fuller story

The number of unplanned admissions for COPD was rising. In 2004, the PCO approached a GP known to have an interest in respiratory diseases management (Dr Taylor). Together with a PCO manager, Mr Turner, Dr Taylor developed a business case for a community specialist respiratory nurse, which was submitted to the Professional Executive Committee (PEC). Although funding had been promised, it was suddenly withdrawn because of an overall budget deficit.

Around this time, a nationally recognised respiratory GPwSI from another PCO contacted Dr Taylor and invited him to a weekend meeting and training event about teamwork in the development of respiratory services. Dr Taylor convinced three PCO managers to attend with him. Inspired by the first meeting, the GP and the PCO managers invited the newly appointed consultant (Dr Thomas) to join them at the second meeting. On the way back from this meeting a local respiratory team ('Inspire') was formed, with a logo, a vision for reshaping of respiratory care *"from diagnosis to death"* and the beginning of a business case.

In 2005 the PCO provided funding to enable Dr Taylor to spend one session per week with the respiratory consultant in the outpatient clinic for training and mentoring. The Inspire team re-submitted a proposal to the PCO to fund a specialist respiratory nurse who would provide training and education in primary care and enhance the skills and capacity for providing respiratory care across the 11 GP practices. The PCO agreed to find the funding from the community matron budget. The Inspire plan was selected by the PBC group as its second project. The PCO Chief Executive was present at the PBC meeting and, according to Dr Taylor, described the Inspire presentation as *"excellent"*. The PBC Group was chaired by a partner in Dr Taylor's practice.

Despite this endorsement, in January 2006 the funding was again withdrawn at the eleventh hour as part of a PCO-wide strategy to reduce overspend. The Inspire team staged a two-pronged protest. Dr Taylor wrote to all the GP practices to make them aware of the decision and solicit their support. He had enrolled on a GPwSI training programme, and emphasised the fact that this training, together with the funding for his mentoring sessions, would be wasted if he did not have the resources to develop the planned services. At the same time, but unbeknown to Dr Taylor, the PCO manager confronted the Chief Executive and argued that failing to fund the respiratory nurse was a false economy in the long run. The decision to pull the funding was overturned.

In Dr Taylor's words: *"We were in business!"*

The Inspire team's business plan for the development of a primary care-based strategy to reshape respiratory services was approved by the PEC in October 2006, on the understanding that the project would be cost neutral by April 2007. Dr Taylor started his GPwSI Diploma course and the specialist respiratory nurse, Sister Thompson was appointed in November 2006.

A phased programme of development followed. Supported by an educational grant from a pharmaceutical company, the Team started to provide education in COPD care for practice nurses and GPs and spirometry training for healthcare assistants. A lead respiratory GP and nurse were recruited in every practice. Based on submissions to the QOF, the quality of respiratory care data was reviewed and 'local respiratory targets' were developed in order to enhance the quality of practice. Despite lack of funding for the extra work, eight of the 11 practices participated in order to improve care. Housebound patients with severe COPD 'exception reported' under the rules of the QOF because they did not respond to invitations to attend the surgery for routine review of their condition (NHS Confederation and British Medical Association 2000), were identified as a source of unplanned hospital admissions and were followed up by Sister Thompson. Oxygen assessment and provision were reviewed.

A healthcare assistant was funded to work with Sister Thompson, and within the local hospital, funding for an additional respiratory consultant and a specialist registrar training post was approved by the Foundation Trust.

By mid 2007, further resources were being actively sought to sustain an expanding programme of activity. A second specialist respiratory nurse and some community staff were required to provide an early discharge scheme. Planning was made particularly difficult by the upheaval following the reorganisation of management structures across Team PCO and a partner Organisation, during which posts were restructured and managers were reallocated, making it almost impossible to get agreement and binding decisions about the future. For example, the temporary lack of a Nursing Director meant that decisions about the appointment of staff nurses to support the early discharge scheme could not be made. Eventually, and quite suddenly, after lobbying and meetings driven in particular by Mr Turner, funding was agreed to appoint several staff nurses to join the respiratory specialist team. Plans for a pulmonary rehabilitation service and a community-based COPD palliative care scheme were considered as future steps, requiring additional resources to prevent the team overstretching itself and failing to deliver on existing commitments.

Throughout the study, the Inspire team continued to meet and remained an active group, with a relatively stable membership. The two other PCO managers continued to attend meetings, and although the Clinical Director no longer attended regularly, he remained a support. A Hospital Trust manager was part of the team and although she did not attend every meeting she was kept informed of developments.

The future

At the end of the case study period, it was clear that the team had several advantages. It was a cohesive team with representatives from the PCO, secondary and primary care. The team had a shared vision, had been able to develop services and secure funding for new members of staff and was addressing the three functions of a specialist service (clinical, educational and strategic). The team and the reconfiguring of respiratory services remained a strong and viable project. It was a priority project for the PBC Group in Team PCO and it was a key project for an 'invest to save' strategy pursued by the reorganised management structure of the two PCOs.

Nevertheless, some questions remained over its future. The expansion of activity required extra resources to ensure future sustainability of the service. The core membership of the team, which had so far proved vital to this expansion, was under threat by the introduction of a clearer demarcation between the commissioning and provider arms of the two PCOs. The project remained a 'pilot', and was still proving its value before it could be formally commissioned. At some point, it was likely that community respiratory services would have to be put out to tender, allowing competitors with cheaper options for all or part of the service to appear. Although no rivals for the respiratory service were yet on the horizon, one local GP practice had already been taken over by a private healthcare company. A further concern was that the developments remained local to Team PCO with some of the initiatives being piloted in the main town. Questions were being raised at PCO level regarding the equity of access to services across the two partner PCOs.

6.6.4 Key features of the development of the respiratory service in Team PCO

Respiratory reconfiguration in Team PCO was driven and enabled by a service development team, with representation from secondary care, the PCO and general practice (by the GPwSI). Local circumstances, particularly the fact that the interests of the local respiratory department coincided with the team's vision, facilitated the team's work towards strategic development of services. Teamwork skills and co-operation within the team, together with the personality of the GPwSI as team lead were important factors. Several interviewees commented on how the GPwSI was a very effective 'champion' of the service as he was *"determined"* but *"not pushy"* and *"not someone who fights for the sake of fighting"*:

> *"I have to say to you without a champion you get nowhere and he's (the GPwSI), you know, a nice man, people like him which helps, you know, we have other GPs and you think 'God if they headed this up it would get nowhere because, you know, they just have that unfortunate interpersonal [skills]'. But he interacts really well, he's not a threat to anybody, he's charming, comes across very well and it's just exactly the right approach."* [Team PCO: PCO manager]

Unlike the service in Merged and Commissioning PCOs, the primary focus was not to establish a separate intermediate clinical service. Instead, the Inspire team concentrated on improving the skills of primary care clinicians and improving liaison across the secondary-primary care interface.

The team as a driver for change

Crucial to the initial setting up of the team and its ongoing development were the recognition by the GPwSI that he could not develop respiratory services by himself. When he was approached by a national GPwSI 'champion' inviting him to attend a weekend event on developing respiratory teams, he actively sought to engage other individuals from the PCO:

> *"…historically the communication between the PCO and GPs in [Team PCO] is not good, it's a culture of 'We'll tell you what to do and we won't listen to what you have to say', and my experience with what had happened previously was [such] that I thought 'Well I'm only one voice, I need back up and I need management back up….' I said 'OK. I want a PCO manager, I want a clinical governance lead, I want the Medical Director to come with me to [the event]' because at that stage we didn't know how secondary care were involved, so we went down to [the weekend event] and they were pleasantly surprised with the whole thing, they thought this was real 'finger on the pulse' stuff, so we then went back and we got the consultant involved and we went back again six weeks later with the consultant for another thing, it was involving in team building, team dynamics, so we've set up the [Inspire] team."* [Team PCO: GPwSI]

Dr Taylor and his colleagues' attendance at these events led directly to the formation of the local respiratory team, as the discussions that they had during the event and while travelling crystallised their thinking around a shared vision for local respiratory services, and started the process of developing the team, deciding on a name and designing a logo. It also appeared to cement firm friendships which meant that team members remained loyal to the team, even when they moved to other posts within the PCO:

> *"I felt very much, a big sense of loyalty to [GPwSI] because we'd all gone off and done this leadership programme and we'd got [the respiratory team] up and running and I actually still attend those meetings sort of out of hours in my own time. I'm not sure how helpful I am but I think it helps them to feel they've got support from senior managers at the PCO."* [Team PCO: PCO manager]

The active support and enthusiasm of individuals from different sectors: the PCO, the hospital trust and general practice gave the team several advantages. Firstly, it meant that the team could draw on a range of different skills and experience (both clinical and managerial):

> *"...you need these clinical champions and people with clout like the [senior PCO manager], like a consultant physician because lone GPs and nurses make no impact at al. You need that complete and utter buy in from the top. And then you need people in the PCO who understand the structure of the PCO and who are the influencers, and which committees to go and barrack, the language of business cases and what switches people on in the PCO wouldn't switch a clinician on and all of that."* [Team PCO: PCO manager]

The potential boundaries between the team members were also reduced, because all but one of the PCO managers involved with developing the team had a clinical background, helping to overcome the potential clinician-manager divide:

> *"...[she] has an overview from the governance arrangements to make sure the governance issues, health care, risk assessment etc, again, she's a clinician, she's been a midwife, so the clinical background is there as part of that, so really we're actually all, we all have a clinical background, which is really quite, but the team works well."* [Team PCO: Senior PCO manager]

The second advantage for the team was that all three stakeholders (the PCO, the hospital trust and general practice) were represented from the outset and involved in the early discussions and negotiations about the proposed shape of reconfigured services. It was not a question of presenting a fait accompli to one party and then having to re-negotiate to overcome resistance or to align objectives. Furthermore, the fact that the team had support from each sector lent it further credibility:

> *"...then of course you present a united front to people, saying well these people aren't just mavericks, they actually have a group who are*

interested in doing it, the PCO see advantages, it's clinically led...."
[Team PCO: GPwSI]

Different members of the team could use their relationships with their own peers to strengthen the team and engage support. For example, when the team's funding was under threat, the PCO managers used their position in the PCO to challenge the funding decisions:

"What helped me was the fact that the team that I have in the PCO were absolutely furious, the amount of work which was, they were developing a business plan and to them it was like 'You can't do that', and that really worked, that really was, if I hadn't had those allies I think I would have found it really difficult." [Team PCO: GPwSI]

"...and then all that budget disappeared [to] block up holes in finance and [Respiratory GPwSI] threatened to totally withdraw and I just took the bull by the horns and went to see the Chief Executive and just said 'Look this is all going to go absolutely belly up if you don't support this man, we need that respiratory nurse' and then suddenly the money was available, and I sometimes think that's what you need, brave people who just think 'Well [***] it, I can't let this go on any longer'" [Team PCO: PCO manager]

Relationship between the team and GPs

The GPwSI also enlisted the support of local GPs and won them over with his clear exposition of the justification for the team's services:

"...some need more convincing than others but the way I sold it to them was to say 'Well, look, remember that three years ago we did not have a respiratory consultant in [Team PCO] for a period of three years, and patients were seeing four different consultants often on a rotation basis' and everyone agreed, I said '...so the more we can support and develop services locally we can guarantee that this is going to be a place where respiratory consultants want to come rather than respiratory consultants don't'." [Team PCO: GPwSI]

Interviews with the consultant six months apart suggested that, although some GPs were initially wary about the GPwSI role, their support for the team developed over time:

"When you read letters of referral, the way they are worded they're obviously saying, you know, 'I [respiratory consultant] must see the patient and not the GPwSI', a few things that have come [the GPwSI's] way that's made it obvious, obvious that people have felt a bit threatened, I suspect it's people just being insecure in their own situation and they've got away with it up until now and now they are realising in their practice there are certain deficiencies as to the way they run their practice." [Team PCO: Respiratory consultant interviewed at beginning of the study]

"Yeah, and the GPs have accepted that. And I think it's because of having a GPwSI who's one of them as opposed to one of us sort of dictating to them. I think in that situation they feel a bit threatened,

whereas in this situation it's one of them doing it. And we had meetings with them only a couple of weeks ago. We had an evening meeting discussing home oxygen and indications and so forth. And from every practice we had at least the doctor respiratory lead and at least one of the practice nurses attend. So each practice was represented. So it's actually worked out very well. So far, touch wood, we've avoided any sort of conflict". [Respiratory consultant, interviewed six months later]

The support of local GPs and their endorsement of the plans by adopting the team as a priority for PBC appeared to have been a key factor in ensuring the team's development:

"Shortly after we had been told we'd got the respiratory nurse specialist money they, we were all called in, all the practices to this meeting saying we're £600,000 in the red we're pulling your funding, without any notice …I basically wrote to every GP and told them realistically I felt this was a wrong way of going about it and really you were throwing the baby out with the bathwater and there was also myself, the musculoskeletal lead was equally affected, and thankfully through the power of all the GPs, everybody said 'Look this is ridiculous, you must carry on', so we carried on…. Bear in mind that a week before that I had presented our plan, an outline of the plan to all the GP practices because we, as a PCO they had to elect five Practice-Based Commissioning projects, one of which was ours and ours was voted on as the number two and obviously got through so, and as I walked out of that meeting the Chief Exec had said it was a great presentation…. Yeah, and then the following week of course finance had said,…'The plan's all right but we're not going to pay you to do it, you know, so we'll pull your funding….' [I think that decision was then overturned] due to basically pressure, every practice solidly backed us so since then we're back on track." [Team PCO: GPwSI]

Relationship with secondary care

The support and active involvement of the respiratory consultant, Dr Thomas, was crucial to the team's success. Although he was initially wary about the proposals, there were significant advantages for him in supporting the plans and the team as they could help him overcome a backlog of referrals so that he could then develop acute respiratory care. The relationship was further eased by the team's decision to avoid creating a separate intermediate care service, either for acute care or a referral service for diagnosis, triage and management. By focusing on the enhancement of skills and co-ordination of care in the existing primary and acute respiratory services, and supporting earlier discharge of patients, time could be freed up to enable the acute respiratory services to address challenges more appropriate to specialist care:

"…he [respiratory consultant] was completely, is still completely supportive and agrees that his life would be so much better if every practice could cope." [Team PCO: PCO manager]

"…he, like me, feels that there's a lot of work in secondary care that is not being done because they just haven't got the resources…[he] says well, OK, we'll be able to fund our sleep [apnoea] service if we're going to be able to save money on this." [Team PCO: GPwSI]

An additional benefit to the hospital respiratory department was that engagement of the trust management was instrumental in the creation of additional specialist posts.

6.6.5 Bringing secondary and primary care closer together

The GPwSI and the consultant both acknowledged that, through working together and through the mentorship relationship, they had developed increased understanding of the challenges and frustrations of working in the other sector. This seemed to reinforce their respect for each other and to reduce the potential gulf between them.

"I think we perhaps in primary care have a very simplistic view of what's going on in secondary care. When you actually look at what's going on in secondary care it is a much more complex set up because of the inter-departmental things that are going on, the politics that go on there, the staffing issues. It is, they have to deal with their problems and they deal with them the best way they can. And when somebody who looks upon that says 'Oh well, this isn't going right, well why has it originated into that pathway'. It's done that way, why? Because of the internal structures within that organisation. So there's a lot of self examination has to go on there." [Team PCO: GPwSI]

"I only see final QOF data, I don't have QOF programmes or anything, so I don't always know what GPs are doing on a day-to-day basis and what they've been pressurised into, or not pressurised into by the PCO, so it's nice to have it first hand and know that I'm getting it straight from the horse's mouth. Because sometimes you're sitting in the Acute Trust and you think 'Well, you know, that doesn't make sense, I wonder why they're doing that', and it's probably because, could have been someone changed the local QOF for example or the local PCO executive is sort of scrounging to save pennies and has just picked on anything that came across his or her desk." [Team PCO: Respiratory consultant]

The importance of relationships

In addition to the relationships that were developed between team members and between the team and local clinicians and managers, wider relationships played a role in facilitating the development of the team. Dr Taylor's decision to approach the respiratory consultant to request help in becoming a GPwSI was partly influenced by the fact that one of his practice partners was a GPwSI working with a cardiologist in the hospital. As the consultant explained:

"…[the respiratory GPwSI] who is the GPwSI who joined me, his [practice] partner was already in a GPwSI heart failure programme with our Clinical Director who is the head cardiologist, so he'd already had

that exposure. He, being the respiratory lead in the PCO, he thought well that's obviously the way to go, so soon after I'd arrived, within a couple of months he sort of cornered me and said could I see my way clear to accommodating him?" [Team PCO: Respiratory consultant]

As the service developed, Dr Taylor and the team benefited from his having a supportive practice partner who was already a GPwSI, and who was also a key member of the PBC group. He also benefited from having access through national networks to other GPwSIs for support and advice.

The active support and involvement of PCO managers was also vital to the team's success. It had been the PCO who first approached Dr Taylor to help with an initiative to reduce unplanned hospital admissions for COPD patients. This provided the team with a firm rationale which they were later able to use to support their business case, and which meant that they could align the clinicians' interests in improving respiratory care with the PCO's financial interests.

It was also helpful that the PCO managers had already witnessed the benefits of a local GPwSI service (in cardiology), and were therefore strongly supportive of the concept and its development in relation to respiratory services:

"My initial thought(s) around GPwSIs were I thought that was the absolute way to go, GPs who specialise, my experience here was of [cardiology GPwSI] who specialised in cardiology and he does a kind of sub-specialty with a consultan. He is a fount of knowledge, his peers look up to him, he helps us, as a PCO, set targets around CHD (Coronary Heart Disease). He's almost known nationally, you know, produces papers and what not and it's just good to have someone like that who has, it helps us in the PCO with the interface between primary and secondary care and, you know, integrated care is the way to go, this definition and this almost dividing line between the two has nearly gone in cardiology with us." [Team PCO: PCO manager]

Some of the contextual factors that contributed to the successful development of respiratory services in Team PCO were outside the team's control (for example, the relatively small PCO with small financial deficit, the well-defined geographical area and the fact that there was a District General Hospital serving the town with a single supportive respiratory consultant). However, the team also acted strategically to promote their services. Because they had a clear vision of what they wanted the local service to provide, they refused to be deflected; for example, they insisted on a community specialist respiratory nurse and would not allow the post to be *"watered down"* into a community matron post which they believed would have reduced the time, and potentially the respiratory expertise, available for respiratory patients:

"[The GPwSI's argument was that]…the respiratory nurses in his experience cannot be all things to all men, they will look after respiratory patients, and the whole remit of the community matron was that they would look after levels, diabetes, you name it they would go in and I'm

sure they're required and they'll be an absolute asset, but for this project to take off it needs a nurse with the only focus in her life COPD and not be called upon to other duties which is what happens in nursing in every field. And we wanted to make sure that this was an absolute dedicated respiratory nurse, and we wanted someone who would have the confidence of other GP practices to allow her in to help, support them in setting up clinics, so we wanted someone with those skills."
[Team PCO: PCO manager]

Team members were aware of the need to advance arguments that would meet the interests and concerns of different parties. For example, the process of securing the local GPs support for the team, so that it was adopted as a PBC project, resulted from a combination of fortuitous local circumstances and persuasive arguments around saving money and improving the quality of local respiratory care:

"I think it was fortunate that the respiratory agenda sort of 'ticked everybody's box' so to speak in so far as we identified a need where obviously respiratory could potentially cut the cost of repeat admissions and various things with it. But equally GPs were understandably concerned because for quite a period of time until this consultant was appointed we had no consultant physician in [town]. So it was really to reinforce the fact that respiratory was a little bit, let's say, 'behind the times' in [town]. So it, as I say GPs voted for that as being one of the top priorities." [Team PCO: GPwSI]

In the same way, the team enlisted support from the PCO and from GPs by their strategic use of other initiatives like QOF: by focusing on COPD patients who, despite being at high risk of hospital admissions, were 'exception reported' under the rules of QOF. By targeting these patients for community specialist respiratory nurse time, the team simultaneously addressed the PCO's concerns to save money, and met clinicians' concerns to improve respiratory care.

Limited organisational change

Team PCO was less affected by organisational change than Merged or Commissioning PCOs as there was no formal merger. However, they were developing joint management arrangements with a larger, neighbouring PCO resulting in considerable organisational upheaval during reconfiguration. Instead of being able to make structured plans and to consult with a range of individuals about the shape of future services, respiratory team members felt that for the respiratory service to develop, it was necessary to grab opportunities before they disappeared:

"You have to remember in the context of all this everything's in a complete state of flux. So because there is no Director of Nursing and the current kind of person who headed up the nursing team in [area] has no authority any longer, we've found it very, very difficult to get agreement about the future...everything's been kind of very, very difficult because the people who need to be in post aren't in post. People are in interim posts and don't carry authority and there's kind of

mixed messages about providers and commissioners and it's just been very, very difficult. But we're hanging on in there and as I say have made progress despite everything." [Team PCO: PCO manager]

"It's been almost impossible to function…And suddenly out of the blue we've been allocated staff nurses. So we haven't asked any questions, we've just grabbed it and minuted it and we're going forward now with the next phase of the plan." [Team PCO: PCO manager]

The introduction of new, more formalised commissioning and contract arrangements was also delaying some of the service developments that the respiratory team were anxious to introduce:

"…one such project has been oxygen assessment [for] which we have developed a pathway, but [which] currently can't be implemented because the pricing structure for nurse led clinics hasn't been done by the hospital. So we've got this ready to run but we can't actually operate it until the financial people get their heads around it and sort it out. So there's a lot of frustrations in that area." [Team PCO: GPwSI]

Arrangements were being made for the complete separation of commissioner and provider functions across the two PCOs (with each PCO to lead on one of the two functions on behalf of both), and this meant that it was not certain whether all of the PCO managers, who had been founder members of the team, would be *"allowed"* to continue as team members:

"…obviously my role is now within the commissioning PCO. So it's kind of been accidental in that the make up of the [team] now includes providers and commissioners naturally. And I'm not sure how long my [senior PCO manager] who, his sole responsibility is […] in the commissioning part of the PCO, and he's involved in [the respiratory team] as well which is very much about provision of service. I'm not sure how long before someone starts to ask questions about our working like that…. It's just that we've been very, very loyal from the start with [GPwSI]. We thought it was a great idea and this was before all the change, all the reconfiguration and we just thought this must go ahead and we joined the team and we went off to [the weekend event] and, you know, we got completely caught up in it all. But how long will we be allowed to still support him?" [Team PCO: PCO manager]

An attempt to ensure the sustainability of the respiratory GPwSI service, by establishing joint working arrangements with neighbouring PCOs had been thwarted by the PCO reconfiguration:

"We kind of did a risk assessment and thought 'Well, the risk to this is, there's only one [Respiratory GPwSI] what if he was run over or won the pools? To make it a sustainable service we really should link with the other two southern PCOs.' So we held a meeting, there were two GPs like [Respiratory GPwSI] with a very strong interest and their PCO managers and we all sat round a table and we, (in) my naivety felt we'd come to an agreement that we would design this together. All go and get the money, go out for recruitment together, joint interviews […] The GPs would work together, the nurses would work as a rota, cover each

others' holidays. And then, you know, the politics changed and mergers and everything and they disappeared like cockroaches in the night, they just went off and [Respiratory GPwSI] and I were left. 'Well what on earth happened there then?'" [Team PCO: PCO manager]

There was also concern that introduction of tighter financial and contractual arrangements within hospital trusts would impact on the mentorship arrangement between the GPwSI and the respiratory consultant:

"There is an issue, and certainly there was an email, I gather, I haven't seen it but I gather an email went out to say 'If any GPs do approach you for mentorship in terms of clinical, you know, developing clinical skills, you know, you must discuss this first with your manager.' ...I don't think the trusts at the moment want to provide clinical leadership within primary care, I mean the opportunities are there, we've got the GPwSIs but there are difficulties because trusts are considering charging for mentorship for GPwSIs. Is that surprising? No. Why not? ...you add another £6,000 for mentorship, this is hardnosed." [Team PCO: Senior PCO manager]

6.6.6 Summary: The three themes in Team PCO

Professional boundaries

The potential negative impacts of professional boundaries were reduced in Team PCO by the early involvement of stakeholders from primary and secondary care and the PCO. This enabled the alignment of interests and development of a shared vision from the outset, which team members from the different sectors could defend to their own colleagues. The clinical background of the managers may have facilitated the process of aligning interests. The development of strong relationships between players through activities such as the weekend courses enabled the team to continue, despite repeated threats to its funding and the instability caused by the PCO reorganisation. Finally, the context in Team PCO offered collaborative advantage to all sectors, including the respiratory consultant who saw the GPwSI service as helping to manage his workload, enabling him to expand his service.

Organisational change

The scale of organisational change was less extensive in Team PCO than in the other case study PCOs and the respiratory team was, to some extent, buffered against any effects by the strong relationships that had developed within the team.

Commissioning and markets

The respiratory team was a pilot and was not formally commissioned. This enabled service development to take place relatively freely, without the constraints of formal commissioning and performance management related to specified targets, which may have contributed to the ability of the Inspire team to develop a range of clinical, educational and strategic activities.

6.7 Merged PCO

6.7.1 The Service setting

Demography

Merged PCO is formed of five PCOs in a semi-rural county with a population of 700,000. It is a relatively affluent area, with some pockets of deprivation.

PCO reorganisation

Merged PCO is formed of five organisations merged into one in October 2006 acquiring a deficit of £50 million.

- County Town PCO: Population 150,000. Urban.

- Coastal PCO: Population 100,000. Rural.

- Affluent PCO: Population 100,000. Rural.

- Central PCO: Population 200,000. Rural.

- Small Town PCO: Population 150,000. Urban/rural.

Organisation of respiratory care

Secondary care services are provided by University Hospital located in the county town, and District General Hospital (DGH) in the small town.

Pre-merger, the five PCOs offered different models of respiratory services. County Town PCO had a well-developed GPwSI service led by a GP who had been a Hospital Practitioner since the mid-1990s. In Coastal PCO there was a recently established GPwSI service. In Affluent and Coastal PCOs community specialist respiratory nurses provided care in the community. In Small Town PCO there was a trained GPwSI but no money to develop the service.

When the five PCOs merged, the three GPwSI services were amalgamated and rolled out across the new Merged PCO, based on the model of the County Town service.

6.7.2 The story of reconfiguration of respiratory services

Table 11.   Chronological overview of key events in Merged PCO

Date	County Town PCO	Coastal PCO	Affluent PCO	Central PCO	Small Town PCO
1990s	1995 GP started working in respiratory outpatients as a Hospital Practitioner.		Under fundholding, a specialist respiratory nurse provided care in a local surgery. When fundholding was abolished in 1997, she contracted with PCO to provide some clinical services and education.		
2002/ 2003	Initiated and facilitated by the University Hospital, the PCO participated in 'Pursuing Perfection' which facilitated a network of clinician/PCO contacts			Specialist nurse from Affluent PCO contracted with Central PCO to provide support and training to GP surgeries.	The PCO used DoH funding to increase GP recruitment by offering a programme with the DGH and the local university to develop specialist skills among GPs.
	With the help of one of the six consultants the GPwSI reviewed referrals to the respiratory clinic potentially suitable for a GPwSI clinic	A GP with a long-standing interest in respiratory care moved to Coastal PCO			GP registrar obtained post and trained with the local University in respiratory care.

2004	In discussion with the PCO, and one of the University Hospital consultants, a GPwSI service was planned. Networking as a result of the Pursuing Perfection project facilitated the project.	GP approached PCO manager to discuss establishing a GPwSI service.	Specialist nurse contracted to provide training and support to other practices, on an ad-hoc basis.	Specialist nurse contracted to provide training and support to other practices, on an ad-hoc basis.	GP training project frozen, because of PCO overspend. Contracts to existing GPs in the scheme honoured. GPwSI worked as partner in a practice.
	Respiratory GPwSI clinic written into PCO business plan and funding procured.	Idea for a GPwSI service progressed as an 'Accelerated Programme' for service development. University Hospital Trust and consultants resisted the service.			
2005	Early supported discharge scheme started by the University Hospital - no apparent co-ordination with existing or proposed community services.				GPwSI training completed, but no money to develop a respiratory service.
	Respiratory GPwSI appointed to provide a clinical service, supported by a specialist respiratory nurse and a healthcare assistant.	GPwSI referral service started supported by a specialist respiratory nurse and a healthcare assistant.			

2006	Community pulmonary rehabilitation services started	Service was underused and concentrating on proving itself. Talks with the PBC Group	.	PCO considered development of COPD services using the independent nurse and a senior specialist nurse in one of the GP practices	GPwSI acted as an adviser to the PCO, but no money to fund a GPwSI service. Specialist nurses offered a respiratory service.
	Respiratory GPwSI service adopted by the County Town PCO PBC consortium as their first major project.				

Date	Development
Oct 2006	Merger of the five PCOs and a 'turnaround team' brought in to redress the deficit of 50 million. PCO manager in County Town PCO, who had been involved in the development of the GPwSI service, took the initiative to develop plans for a Merged PCO-wide model of respiratory care based on the results from the County Town PCO service and built around the GPwSIs in County Town, Coastal and Small Town PCOs. Implementation group, led by the County Town GPwSI, set up, comprising the three GPwSI and three specialist nurses, but excluding consultants.
Feb 2007	Plans involving an ambulatory service covering the whole of the new PCO approved by the Turnaround Team. The service included a referral service and community pulmonary rehabilitation. Involvement of nurses in Affluent and Central PCOs was part of the plan, but clarification on-going. University Hospital management and consultants strongly opposed the plans because of loss of referrals, Some resistance among consultants in DGH, previously involved in training the GPwSI in Small Town PCO.
July 2007	PCO-wide service started up. Discussions with consultants and Hospital Trust management ongoing and relationships still fraught.

6.7.3 A fuller story

The story of respiratory service development in Merged PCO evolved from separate services in the five PCOs, which merged in the reorganisation of 2007. We give an overview of the developments in each PCO separately, and then describe the main features of the development post-merger.

County Town PCO (Pre-merger).

This PCO had the most mature and developed respiratory service at the time of the merger. A prominent player is the GPwSI, Dr Matthews. He had a long-standing interest in respiratory care and worked as a Hospital Practitioner in the outpatient department of the University Hospital since 1995. Through this work he formed a strong professional and personal relationship with one of the consultants, Dr Moffat.

In 2002, consultants from University Hospital took the initiative to involve County Town PCO in a 'Pursuing Perfection' pilot project, facilitated by a member of the hospital trust's development unit. Dr Moffat was the lead respiratory consultant, and the hospital specialist respiratory nurses working in his unit were involved. They engaged PCO managers (including Mr Morton, who came into post shortly after the pilot was launched), Dr Matthews, as a lead GP in respiratory care and other primary care practitioners involved in respiratory care. The group examined respiratory care from different perspectives in both secondary and primary care, and considered how a multi-professional team spanning the two sectors could develop service to improve patient pathways.

In 2003 this initiative spurred Dr Matthews and Dr Moffat to look at data on referrals for respiratory care, and to explore the volume of referrals potentially suitable for a GPwSI service. The data were encouraging, and with the help of the PCO contacts they had established during the Pursuing Perfection project, they developed a proposal to fund a GPwSI service. Mr Morton had good experience and knowledge of the GPwSI concept from existing initiatives in other clinical areas. The proposal was written into the PCO business plan and funding secured in 2004.

The GPwSI service, with Dr. Matthews supported by a specialist respiratory nurse and healthcare assistant, provided a clinical service, and educational support to GP practices. GPs referred to the service, and consultants knew about Dr. Matthews' work in the outpatient department in their hospital and generally accepted his expertise. However, opinion among the six consultants was divided as to whether the skills of a GPwSI, no matter how experienced, were adequate in providing specialist care. The lack of officially recommended accreditation procedures for GPwSIs at that time, fuelled challenges to the role, but Dr Moffat's advocacy was supportive.

With the merger, in 2006, the situation changed.

Coastal PCO.

There was limited development of respiratory care in this PCO until 2003, when a GP with long-standing expertise in COPD care, Dr. Manning, moved to the area. He was a prominent member of a network of primary respiratory care professionals and GPwSI enthusiasts, and on moving to the area, approached the PCO informally about a GPwSI service.

Late in 2004 the PCO decided to develop a GPwSI service as part of a DoH funded 'Accelerated Development' Programme. Two PCO managers from the PCO, Dr. Manning and a specialist respiratory nurse attended the training provided. The training was disappointing as it was targeted at Human Resources staff drawing up job descriptions in accordance with Agenda for Change criteria (Department of Health, 2004a), and had no clinical content. Nevertheless, the group used the time to sit together and think through the new service.

Returning to their PCO, the group encountered problems with the University Hospital Trust. They wanted to base the service in premises owned by the hospital trust in Coastal PCO area, hoping to establish a link and secure the support of a consultant. However, the hospital trust management and consultants opposed the idea and suggested the money should be used to set up a hospital-based service. In the end the matter was resolved, but only after a long process of confrontational meetings. Funding was procured in 2005.

The service started in November 2005. One year on it was still being established, with work remaining to engage GPs and hospital clinicians and develop their confidence in the service. Although the model for the service was similar to the GPwSI clinic in County Town PCO, it was perceived as not having been *"set up in anything like the same way"*.

With the merger however, the fortunes of the GPwSI service were to change.

Affluent and Central PCOs.

In these areas, service development took place around specialist nurses, including one nurse, Sister Middleton, who contracted independently with both Affluent and Central PCOs to provide clinical and training services in respiratory care.

Under fundholding arrangements, Sister Middleton had worked as a respiratory nurse in a respiratory-interested practice in Affluent PCO. She was also a nationally recognised respiratory trainer. When fundholding was abolished in 1997 Sister Middleton, based on her expertise and contacts in clinical care, education and research, contracted independently with the PCO to continue her PCO-wide clinical and educational services. In 2002 she also contracted with Central PCO to provide training and clinical support to primary care staff.

By 2005 Affluent and Central PCOs were working to co-ordinate existing respiratory services to form a strategy for the management of COPD. These services incorporated Sister Middleton's work, and in Central PCO, the

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expertise of a senior respiratory specialist nurse in one GP practice. In Affluent PCO there were also initiatives under development, such as a Meteorological Office health forecasting to alert patients and services to onset of cold or damp weather conditions, known to exacerbate COPD.

These plans were put on hold when the merger was announced.

Small Town PCO.

The story in Small Town PCO started in 2003 with a shortage of GPs and several unfilled vacancies. The PCO obtained funding from the DoH for a 'Parachute PMS' project to attract young GPs to the area. The money provided short term contracts for GP registrars to train and establish themselves as principals or salaried GPs. Two PCO managers, in order to maximise the potential for building skills and capacity among GPs for service development, linked up with a local university to enable young GPs to develop their specialist clinical interests and skills, thus providing a pool of specialism within the PCO. A GP with an interest in respiratory care, Dr. Miller, was appointed on a one year contract which included three days per week working in her 'host' practice, one day training at the university and one day working alongside a mentor consultant from the District General Hospital, with whom she developed a good relationship.

The project was frozen after a year because the PCO was overspent, but the contracts of GPs already on the scheme were honoured. Dr Miller finished her training, was accredited as a GPwSI according to locally developed criteria, and obtained a job in a local GP practice, where she continued to work. However, with the funds frozen there was no money for her to use her skills to provide a respiratory GPwSI service. She was frustrated and disappointed.

With the merger announced in 2005 her situation was to change.

The merger: the GPwSI service develops, but in what form?

In 2006, the decision was made to merge the five PCOs into one county-wide PCO which, it emerged, had inherited a massive deficit of £50 million. A Turnaround Team was brought in to redress this imbalance. This added another challenge to the task of co-ordinating a range of sometimes fragmented services in all clinical areas across the five PCOs; however, it also presented an opportunity to pull together and rationalise services across the whole of Merged PCO.

This opportunity was seized by Mr Morton, who had been appointed as a commissioner in Merged PCO. He saw an opportunity to develop the respiratory services throughout the Merged PCO, modelled on the GPwSI service he had helped to develop in County Town PCO which had reduced referrals to hospital outpatients. He *"took the idea to Turnaround"* who gave him the go-ahead to develop a business plan.

His first move was to form an 'Implementation Group' to oversee the developments. Dr Matthews, the County Town PCO GPwSI was asked to chair the Group, which also comprised Dr Manning and Dr Miller and

specialist nurses from these PCOs. A potentially significant omission was Sister Middleton, the specialist nurse working in Affluent and Central PCOs, and, importantly, none of the respiratory consultants from either of the hospitals were included.

The PCO-wide GPwSI service was to comprise an ambulatory referral service and community pulmonary rehabilitation led by the GPwSIs, with specialist nurse and healthcare assistant support. The plans were based on removing outpatient and follow-up work from the hospital trusts and transferring this activity to primary care. The Turnaround Team accepted the project as a pilot which, therefore, did not have to go out to tender and be formally commissioned. It was finally accepted in February 2007 and started up in the summer of 2007.

The future

At the end of the study, the PCO-wide GPwSI service as a Turnaround initiative was still under development, with a number of issues outstanding, the most pressing issue of which was the resistance from the University Hospital consultants. The service was not formally commissioned, but ran as a 'pilot'.

The loss of secondary care support, together with the still undeveloped co-operation between the PCO and PBC Groups, may make the service more vulnerable in an increasingly contestable local health economy when the pilot service goes out to tender to be formally commissioned.

6.7.4 Key features of the development of the respiratory service in Merged PCO

Of the four cases, the changes brought about by the merger had the most marked impact in this PCO. The interests of a large number of players, who had developed a way of working in specific and smaller PCO areas, had to be reconsidered and aligned in a new context. The introduction of a Turnaround Team to address the large budget deficit was a major factor. The service cuts and focus on cost alienated both primary and secondary care from the PCO. It also disrupted relationships between the GPwSI service and the respiratory consultants. This prevented alignment of interests around the development of the GPwSI service.

The merger and Turnaround

The size and scale of the merger led to considerable uncertainty about structures and processes within the new PCO and about how existing staff and structures would be accommodated. As late as a month before the merger, a respiratory nurse in one of the hospital trusts in the area commented: *"It's odd, I think the PCOs don't know yet, I don't think they know who's going to be their bosses, they don't know who's going to be running which services"*. This was echoed by a PCO manager interviewed at that time who said *"We don't yet have a substantive Chief Executive, we only have a transitional one, we don't know yet when they're going to come to that, so we don't know what the structure really will look like or where*

we will be placed in it." The months after the merger were characterised by frequent changes of staff at all levels, with some staff filling vacancies for short periods and then deciding to leave or being made redundant. The contacts and relationships interviewees had used to progress development were disrupted.

The large financial deficit that the new PCO inherited played a significant part in creating a sense of unease and disaffection. Study participants from PCOs that had previously been financially solvent or only had a small deficit, resented having to share the responsibility for the substantial debt and having to be part of the service changes which were driven by the need to reduce it. There was a sense that many were shocked by what had happened and by the way that the new PCO's decisions about services appeared to be based solely on financial considerations:

> *"I don't think what any of us realised was that the new PCO was going to start with a deficit of over 50 million pounds, one of the largest PCO deficits in the country and the new PCO came in with a very aggressive policy to save money to offset the deficit and they produced something called a Turnaround plan to achieve this and there were accountants brought in by the Strategic Health Authority to run, to support this process, and there was very little consultation on this plan"* [Merged PCO: GP]

The introduction of a Turnaround team, as a short term measure to bring the PCO budget back in balance, proceeded separately and ahead of the development of commissioning structures as a longer-term mechanism for service development.

> *"Our commissioning arm, to be perfectly honest, is in a right mess… There are a significant number of commissioning posts in the structure that are actually vacant, and we've got an Acting Commissioner in at the moment who's come up from the Strategic Health Authority."* [Merged PCO: PCO manager 1, a few months post-merger].

The Turnaround process also took precedence over the development of commissioning:

> *"It's all very new, all this tendering and all the rest of it, particularly with being Turnaround,…I suppose there are other areas of the country which are far more organised in terms of their approach to commissioning. Because a lot of what we are doing as a provider and actually our commissioning side…is driven purely by the need to save money…we haven't got into the real commissioner/provider split yet.''* [Merged PCO: PCO manager 3]

On the one hand, and from a PCO managerial perspective, the Turnaround introduced a structure, which facilitated a systematic PCO-wide overview of service developments and their financial implications:

> *"….there are many people involved in the Turnaround Plan and in the programme are big pieces of work that people have responsibility for. That in itself is invariably a pressure. But I think there is a need to keep*

that pressure and the momentum up in order for things not to slip. But that in itself, the reporting and processes and that, you know, can in itself I guess help to drive innovation, but you would hope not to the extent that, it becomes the be all and end all of everything else."
[Merged PCO: PCO manager 2]

On the other hand, there was awareness at PCO level that this emerging strategy and the complex mechanisms for its implementation were not shared with providers, and that this had an impact on longer-term service development:

"...and then you come across a practice somewhere in [area] and they say 'We don't know what Turnaround is, we don't understand what Practice-Based Commissioning means for us',...'Tell us what's going on', and you think 'oh my God I should have been out' It's not my responsibility but somebody should have been out and so I may have gone to talk to them about, yes respiratory services and I end up actually taking them through the last sort of six months of reconfiguration and what things mean." [Merged PCO: PCO manager 1]

One outcome of Turnaround's focus on short-term savings and separation from mechanisms for longer-term strategic development was an exacerbation of tensions and conflict among the main players in respiratory service development, particularly between the University Hospital consultants and the embryonic GPwSI service.

Widening tensions

Before the merger and the expansion of the GPwSI service there was general support for a GPwSI service in the Small Town DGH, whereas consultants in the University Hospital were divided. The DGH took referrals from two neighbouring PCOs and their dependency on Merged PCO referrals was less than in the University Hospital which, as a teaching hospital and tertiary referral centre, also had more staff and more activity to protect. Active opposition from some consultants was offset by the support of the consultant who had mentored the GPwSI in County Town PCO. He argued in terms of a need to build skills in respiratory care among GPs:

"...I believe that what [Respiratory GPwSI County Town PCO] does at his clinic is a very good way of increasing the respiratory expertise available in the community, there is an argument about 'actually then he's just doing our work and we're going to be deprived of funds [in order] to pay for his clinic', I don't really sort of care about that bit of it in a sense, because for me the number one priority is to make sure that respiratory patients get the care they need". [Merged PCO: University Hospital respiratory consultant 1)]

When the expanded PCO-wide GPwSI service was set up, however, the consultants in both hospitals closed ranks to defend the boundary of their territory against the new service. The push towards cost savings involved taking services and funding out of secondary care and locating them in primary care settings. This had an impact on service development in both hospitals, but particularly in University Hospital:

"Well, things certainly seem to have become much more difficult in the last nine to eighteen months, I think, within the secondary care setting, primarily because one of budget cuts and the (Hospital) Trust being forced to make savings. And within the last few months there have been, I suppose, two significant developments which are adversely affecting the (respiratory) department. One is the PCO insisting on calling up our follow-ups and outpatients, and the other is that they are also wanting to reduce our new patient numbers on a department basis and that's partly based on a plan to expand the GPwSI service." [Merged PCO: University Hospital respiratory consultant 2]

There was a sense of lack of involvement and information sharing around developments from the secondary care perspective:

"It's not very transparent I'm afraid. …As I say, the few meetings we have had, the little correspondence we have had with the PCOs about the GPwSIs, information has not been forthcoming. They haven't been able to, or they haven't chosen to, discuss or share information with us. So it's been a disappointing process really." [Merged PCO: University Hospital respiratory consultant 1]

Two strategies were described by respiratory consultants to address the situation. One was to move away from the GPwSI territory and move into increasingly specialist areas, such as interventional bronchoscopy, and more aggressive techniques in lung cancer and extension of the sleep service to include neuromuscular patients:

"Some of these (ideas) are, you know, in the air, some of them are actually things we already know we'd like to do and have said how we'd like to do them. My view is that if you don't start to think about doing that for your own service everybody starts catching up with you pretty quick. If you regard the developments of things like GPwSI clinics as a threat, which I don't, but if you do then the best person to stop that being a threat is yourself. There's no point in just moaning that they can't do that because they're not specialists. Actually, yes, they can do that and so we need to do something else." [Merged PCO: University Hospital Respiratory consultant 1]

However, according to other consultants, this strategy was made difficult in the face of continuous cuts from the PCO and Turnaround Team. The reduced funding from the PCO was a factor in the Hospital Trust financial recovery plan, which impacted on the respiratory departments' ability to organise acute services in a cost-effective way and free resources to enable longer-term service development:

"If we have got too few nurses on the (High Dependency) Ward then acute respiratory failure patients have to go to ITU (Intensive Care Unit), which is expensive and dangerous. On the High Dependency Ward it's cheaper and less dangerous, but, you know, if we've got one trained nurse on at night we can't do it. At the moment we are seriously suffering from the Trust's financial recovery plan which has prevented any bank agency cover for absent staff and is not replacing any staff

who leave by natural wastage. There are people doing two or three jobs in here at the moment, which has an inevitable effect. I'd say that the major weakness at the moment is, we need to expand some services which we do have but which are not sufficient, that don't have the sufficient capacity. One of them is sleep apnoea services which we'd like to expand in terms of volume, but also to expand into more the area of more specialised assisted ventilation such as neuromuscular patients. We can't do this without significant developments, proposals and funding." [Merged PCO: University Hospital respiratory consultant 2]

The most prominent strategy therefore was to defend their boundary against the GPwSI service. While the principle of specialist functions located in primary care was accepted by both secondary care clinicians and managers, the question arose about where the new boundary was to be drawn between a GPwSI and specialist expertise. Another argument concerned the need for specialist supervision and support.

As the plans to expand the GPwSI service developed, and the implications for the University Trust, in terms of reductions in volume of patients, became clearer, the Trust, including managers and clinicians, increasingly resisted the developments, and the conflict became entrenched. Towards the end of the study period however, the appointment of a new Chief Executive in University Hospital, who seemed more willing to negotiate with the PCO and accommodate different interests, gave hope that there might be a resolution to the conflict.

Primary care support: the role of PBC

On the other hand, the respiratory GPwSI service was forming links to the embryonic PBC structures and was being adopted as a priority project across the Merged PCO. PBC Groups were forming throughout the PCO area in the months after the merger, partly as a united response to the sense of alienation from the PCO and the lack of involvement in PCO decisions and also to be able, in the words of a GP respondent, to *"pre-empt and hopefully reduce the impact of outside providers being used."* The systems, however, including the PBC Groups' relationships to the PCO, were undeveloped:

"Well, I think things have moved on extremely slowly and we don't have any clear evidence that the PCO is involved in very active support for Practice-Based Commissioning and we're unclear where Practice-Based Commissioning is going. We, as commissioning groups, we've actually got much closer co-operation with the other groups in the pan-PCO area and the umbrella groups have formed and looked at where they're going. One of the perhaps consequences for that is that jointly respiratory services are being put through the whole area and not just in the (County Town) PCO. Now to some extent that is with the support of the PCO and certainly the Chief Executive has begun to come to some meetings with the PBC umbrella group and become more involved. But up until quite recently, very few Practice-Based Commissioning projects, like introducing new innovations, re-using savings from last year, virtually none have been approved and nothing has moved forward. There's a lot of stagnation." [Merged PCO: GP]

There were thus signs that PBC could become a vehicle of communication between primary care and the PCO and a longer term support for strategic developments such as the GPwSI service.

Meanwhile, the lack of co-operation between secondary care, primary care through PBC, and the PCO increased the likelihood of further fragmentation of services, as increased numbers of providers tendered for bids. One of the PBC groups had formed a 'Local GP Practices plc' to protect their interests from alternative providers in the face of the Turnaround process. The lack of co-operation from the Hospital Trust disadvantaged the 'Local GP Practices plc's' ability to compete in the increasingly contested market, because bids put in without secondary care input were less likely to be successful.

GPwSI position: between secondary care and the PCO:

There were divided opinions among the three GPwSIs, who were to deliver the new PCO-wide service, as to how to position themselves in the system. Whilst PBC support was acknowledged and valued, there was lack of agreement about the significance of the hospital trust opposition. Whereas Coastal and Small Town PCOs' GPwSIs were positive about the developments because it gave their attempts to develop their own service renewed impetus, County Town PCO GPwSI, who was leading the development of the new service, had grave reservations:

> *"Well, I think I am being pulled in several directions at once really and I think it is quite hard. The thing has sort of developed a momentum of its own which has been quite difficult to control, and, you know, I feel quite uneasy because I feel in a sense I have, well I feel as though I have let down my secondary colleagues in a way, because there is no doubt that the PCO wants to take money away from secondary care services, but that was not my intention ..I think the area I don't know the answer to is whether the (University Hospital) are going to continue to be hostile or whether we can actually agree to the principles of working together. If we can't agree principles of working together I'm not sure the thing is viable.... I think it will fragment the service and I think it will be difficult for us to stand alone without support from links with secondary care. I think we need them, for what we need to do to be able to refer on difficult patients, and we need them to co-operate in care pathways for example on hospital discharge, and if that doesn't happen then it's very difficult to see how it may work."* [Merged PCO: County town GPwSI]

6.7.5 Summary: the three themes in Merged PCO

Professional boundaries

The contest of territory between the GPwSI service and the hospital respiratory services was a particular feature of Merged PCO. This contest was exacerbated by a range of factors: the cuts in funding for secondary care services, the lack of involvement of respiratory consultants in the

development of the service, and a history of resistance among a number of the consultants to a GPwSI service. The contest was a barrier to service development. It also restricted the scope of the GPwSI role in terms of building a comprehensive patient pathway and precluded the engagement of local secondary care expertise in building primary care capacity and leading strategic change.

Organisational change

The scale of the merger, together with the need to address the large budget deficit, made service development in Merged PCO particularly difficult. However, the merger also created an opportunity to roll the GPwSI service out across the new and larger PCO.

Commissioning and markets

The role of the Turnaround Team and the short-term measures taken to reduce the large budget deficit took precedence over the development of commissioning structures in the new PCO, and the GPwSI service was established as a 'pilot' linked to the Turnaround process. The burgeoning PBC Groups' support for the GPwSI service strengthened its position, but the lack of effective communication between the PBC Groups and the PCO prevented these Groups from fully realising their role in service development.

6.8 Commissioning PCO

6.8.1 The Service setting

Demography

Commissioning PCO covers a population of 300,000 people in a mixed urban and semi-rural area. There is one major area of deprivation and smaller pockets of deprivation within the geographical patch covered by the PCO.

PCO reorganisation

The PCO is a commissioning only PCO; community services are provided by a local Community Trust. The neighbouring PCOs with whom there have been historical links were part of the county-wide mergers in 2006, but Commissioning PCO was not externally reconfigured. However, there was substantial internal restructuring in 2007.

Organisation of respiratory care

There were around 60 GP practices.

Secondary care respiratory services are provided by a University Hospital Trust which is located on two sites, one within the PCO and one in a neighbouring PCO. A regional reorganisation of secondary care services is on-going. This is unlikely to affect the hospital services in Commissioning

PCO, but there are concerns about the future of the hospital within the neighbouring PCO.

A nurse-led community respiratory team commissioned from a local community trust was set up in 2006.

6.8.2 The story of reconfiguration of respiratory service

Table 12.   Chronological overview of key events in Commissioning PCO

Date	Development
2003-2004	Using staff from the existing intermediate care service managed by a community trust, a COPD 'Hospital at Home' pilot was set up which resulted in an *"impressive"* reduction in bed days.
	The PCO established 10 Clinical Reference Groups (CRGs), covering a range of LTCs (including a Respiratory CRG).
2005	A nurse from the successful COPD pilot was seconded to assist the PCO reconfiguring respiratory services and to model the workforce needed to provide a robust 'Hospital at Home' service. A parallel task was the development of a COPD clinical pathway defining referral thresholds for safe care in the community, emergency admission procedures, and hospital management.
2006	Recurring funding was secured for a 13-strong community respiratory team as part of the PCO's package of 'prevention of unscheduled care' projects.
	The clinical team leader, Sister Christie, was appointed by the community trust in May and the clinical service was launched in September. The services initially provided were 'maintenance' (education and help with self-management) and 'rapid response' for the acutely ill patient needing immediate assistance during an exacerbation. A limited community pulmonary rehabilitation service started in December.
	The respiratory service was adopted as a PBC project in one of the PCO's three PBC localities.
2007	Plans to develop the community team's work by using Met Office forecasting, reviewing the provision of oxygen to respiratory patients and providing end-of-life care were hindered by the team's workload and by internal restructuring at the PCO which led to several months delay in driving services. The respiratory consultants approached the PCO to discuss appointing a consultant respiratory physician to work in both the acute hospital and the community, but plans were eventually shelved.

6.8.3 A fuller story

In 2003-4, a small pilot project of COPD Hospital at Home was undertaken using nurses from the existing intermediate care team provided by the community trust. This pilot project achieved good results in terms of saved bed days, and the team built up good relationships with the secondary care respiratory health professionals.

Meanwhile, adopting a recognised approach for ensuring clinical input into developing integrated services for people with LTCs, the PCO set up 10

CRGs. (Clinical Reference Groups are disease-specific local advisory groups which may include professionals, patients and managers). The Respiratory CRG was adult secondary care focused, and chaired by a respiratory consultant, Dr Collins. GPs did not attend the early meetings: the reasons for this are unclear, but it was suggested that the lack of funding for GP locums to facilitate attendance played a role. The paediatric specialist respiratory nurse was co-opted later on the insistence of other CRG members.

In 2005, a PCO commissioner, Mr Chapman, cognisant of the national and local trends towards increased hospital admissions for COPD, looked at the pilot team's activity data and data on saved bed days, and used this to model the workforce needed to provide the service across the PCO throughout the year, taking account of the times of peak pressure. A nurse from the COPD pilot was seconded to the PCO to provide clinical input and advice on service specifications and protocols. Clinical pathways and protocols were developed (in discussion with stakeholders including the ambulance service) covering safe care in the community and referral thresholds, and management within the hospital Medical Assessment Unit.

In 2005-6 a community respiratory team (i.e. additional to the existing intermediate care service) was commissioned from the Community Trust within the PCO's 'prevention of unscheduled care' strategy. The team would have 13 members of staff (10 clinical and three administrative or support). The main driver was the need to reduce hospital admissions, with a target to reduce admissions by 30% over what had already been achieved by the pilot project. In addition to the financial imperative to reduce acute admissions, the increased pressure on space at the hospital site, following closure of non-acute beds, was also a driver. Recurring funding was secured for the community respiratory team; our informants were unable to provide details of this process.

In May 2006 a specialist respiratory nurse, Sister Christie, who had long-standing connections with the secondary care services in the University Hospital was appointed to lead the clinical team, and services started in September. The initial focus was on two *"arms"*: a *"maintenance arm"* to provide patients with education and support for self-management and a *"rapid response arm"* for unwell patients who needed immediate assistance.

In December 2006, the existing limited pulmonary rehabilitation programme (based in the hospital) was extended to provide some community-based rehabilitation for more patients. The PCO's commissioner for respiratory care (Mr Chapman) was responsible for developing these initiatives. Subsequently, the respiratory service was adopted as a PBC project in one of the PCO's three PBC localities.

In 2007, the team started to take direct referrals from GPs in addition to referrals from secondary care. However, the team's heavy workload and staff vacancies hindered the proposed development into three further areas: using Meteorological Office health forecasting; reviewing long-term oxygen use and improving end-of-life care for respiratory patients. Progress was also hindered by internal restructuring at the PCO: Mr Chapman who had

been heavily involved with the community respiratory team from the outset moved to another post, and there was a delay in designating a successor.

The respiratory consultants approached the PCO to discuss appointing a consultant physician who would split their time between the acute unit and the community, arguing that it would help to bridge the gap between hospital and community and to reduce outpatient appointments (part of the PCO's strategy), but the plans were eventually shelved.

Sister Christie, concerned that she needed to retain her clinical skills despite her administrative workload, started her own clinic held at the same time as the hospital consultants' community clinic, with the aim of seeing some shared patients and facilitating case discussions.

The future

In an environment of increased contestability, the community service appears relatively secure as the recipient of considerable PCO investment, from which returns are expected.

Despite the PCO having a broad vision of what the community team would do, the emphasis on achieving specific targets led to an over-concentration on clinical services to the detriment of on-going training of team staff, education of primary care clinicians and involvement in strategic service development. The service has been adopted by one of three PBC Groups, but lack of GP engagement at design level is a further barrier to a strategic expansion of team activities beyond COPD admission prevention.

6.8.4 Key features of the development of the respiratory service in Commissioning PCO

A Commissioning PCO-led service: the impact of performance management

The main driver for reconfiguring respiratory services in Commissioning PCO was the need to reduce hospital admissions, as part of an overall strategy to reduce unscheduled care in line with national policy, and prompted in part by the shortage of space at the hospital site. COPD was identified as a major cause of unscheduled admissions and an earlier pilot had demonstrated what could be achieved by a community service dedicated to reducing admissions. The PCO therefore commissioned a service from the provider Community Trust, to secure these benefits on a longer-term basis. The service's performance was assessed by the Commissioning PCO in terms of the number of 'contacts' made (the PCO's model equated a certain number of contacts with a corresponding number of hospital admissions saved).

There was a perception by the Sister Christie that they were under *"immense pressure"* from the PCO. She identified a persistent and unresolved conflict between the need to meet performance targets and the need to provide the staff with ongoing professional development that would

ensure a quality service. This pressure was felt during the period of establishing the service:

> *"...it's been very, very pressurised and that's had, you know, quite a detrimental effect on team members.... I think because [area] were under an agreement to provide a service and the PCO were very, are very, you know, pro what's happening, deadlines, action plans, when's it going to happen, they want it rolled out."* [Commissioning PCO: Specialist respiratory nurse]

The pressure continued when the service became operational and took the form of regular monitoring of patient throughput.

The PCO's original vision was that the service would contribute to prevention of admissions *"holistically"* by addressing the broader determinants of stability in respiratory conditions e.g. by providing on-going 'maintenance' care and pulmonary rehabilitation to more patients. However, the high workload in providing the 'rapid response' service (to which performance targets were attached) made it difficult to develop these other areas:

> *"We met recently within our service to look at oxygen requirement because we're very aware that patients who are on long term oxygen haven't been well assessed, that there are lots of problems out there in the community with those patients and I actually, just thinking actually we can't really do that because in fact what we need to do is go back to the PCO and say 'actually, we need funding for this' because, you know, otherwise I'm going to get my fingers burnt if we try and create another new service within our service just on the goodwill of people saying 'Well we'll drop a clinic there' and, you know, you try and meet demand".* [Commissioning PCO: Specialist respiratory nurse]

> *"To be absolutely honest, we haven't got time to pick it up [review of oxygen] unless we get some funding and time aside to do it."* (Commissioning PCO: Specialist respiratory nurse interviewed six months later]

Close relationships between the Team and secondary care

A strong feature of this case was the close links between the community respiratory service and the respiratory consultants, and the comparatively weak links with the GPs. In early interviews, Sister Christie and Mr Chapman both emphasised the need to involve GPs in spite of the difficulties of, for example, facilitating GP attendance at the CRG. On the other hand, Sister Christie and her mentor, Dr Collins, would both have liked the service to be even more integrated into secondary care. Sister Christie perceived the relationship with the secondary care consultants as vital in terms of maintaining and developing her expertise:

> *"I don't know how you could run a service without it to be honest...I think we'd be scuppered really...you get it by rubbing along with people who know more than you do, you know, you glean and pick up information from them so that you become very specialist, you know, so*

that your knowledge is also very specialist and superior to primary care."
[Commissioning PCO: Specialist respiratory nurse]

Previously, Sister Christie had held a respiratory nurse post within the University Hospital, and she missed the lack of daily informal contact with Dr Collins and the respiratory consultants:

"My ideal would be that my service shared, was co-located with the chest physicians, I guess if it had been seconded by the commissioners in secondary care and we'd set it all up in secondary care, then you wouldn't have all this Trust problem…But the PCOs are so keen on getting things out into primary care so do they then miss that robust influence of secondary care?" [Commissioning PCO: Specialist respiratory nurse]

In response to concerns she had expressed about the distance she perceived between the community service and secondary care (*"we're missing the proximity of having the respiratory physicians as our close allies"*), the respiratory consultants had started to take it in turns to meet the nurses on a monthly basis to discuss clinical cases as a way to develop rapport and increase the team's expertise.

Mentorship and clinical supervision of Sister Christie were currently provided by Dr. Collins, with whom she had a long-term good working relationship. This was a slightly anomalous relationship in that they were employed by different trusts. Differences over a separate matter between Hospital and Community Trust managers had brought this anomaly into the open and there were moves to formalise this mentoring relationship through a formal contract and payment. Sister Christie and Dr Collins were keen for this relationship to continue and ideally to develop further: but plans to enhance the consultant role with the service had encountered some resistance from the Community Trust:

"I felt that the consultant role should be enhanced in fact because there are, it's more than just educational in that there are governance issues and development of the service issues, and so greater integration would in fact be helpful but there have been some barriers to that from the management of the [community trust]." [Commissioning PCO: Respiratory consultant]

Dr Collins also believed that it would be helpful if the community specialist respiratory nurses spent time on the Medical Assessment Unit and if the hospital specialist respiratory nurses were able to spend some time working in the community, facilitating greater awareness of both hospital and community, but acknowledged that high workloads prohibited this.

The close links between the community respiratory team and the respiratory consultants appeared to be eased by the perception that the community service was not a threat to secondary care services, although the consultants emphasised the need to see a full range of respiratory patients (including those with COPD) to maintain clinical expertise. One respiratory consultant interviewee explained that there was more than enough work for them as specialists, even with the reduction in admissions. Additionally

they anticipated an increase in workload would follow the acute services review.

However, there were limits as to how closely the service, through the personal relationships of Sister Christie, was allowed to enter the territory of secondary care. Her request to become formally part of all of the hospital team's meetings, rather than attending occasionally when invited, invoked antagonism; suggesting that this action was seen as pushing a boundary too far.

A development towards the end of the study period meant that Sister Christie started to hold a community clinic once a month at the same time as the respiratory consultant. This enabled them to see some patients together and also to discuss complex cases face-to-face. Again, the fact that they were employed by different Trusts was an issue, resolved by counting patients seen together as consultant clinic activity for financial purposes, even though this may have implications for the community respiratory service's performance targets. The arrangement may also be jeopardised if further concerns are raised about the need for formal agreements to cover cross-trust (i.e. hospital trust and community trust) working. At this early stage the arrangement was agreed informally:

> *"It just happens to be one of the other chest physicians who comes down on a Wednesday (and there is no problem with that) because I asked their (Community Trust manager) permission if I could do it and they said yes that's fine, but there's no agreement on that."*
> [Commissioning PCO: Specialist respiratory nurse]

Change and reorganisation of the PCO: reduced support for the community respiratory service

The close personal working relationships between respiratory consultants and the community respiratory team also helped sustain the team through a period when PCO management and support fell away because of an internal PCO reorganisation. There was also wider service reconfiguration, which made the system difficult to manage for a range of players.

A wide-ranging review of secondary care services in neighbouring counties was in progress, which was expected to have knock-on effects on hospital services within the PCO, although at the time of the study it was unclear what the outcome of the review might be. In the meantime, there were also changes within Commissioning PCO, prompted partly by lack of space at the University Hospital site and relocation of services between hospital sites. A number of private providers were also known to be ready to bid for tenders.

Interviewees from both the PCO and the hospital trust expressed confusion and uncertainty and were concerned about radical and unpredictable changes:

> *"Well at the moment it's quite difficult because you're trying to plan and develop services which may change in two years time…the other development we've got happening on this site is the development of an*

urgent care centre…which again is an unknown quantity. They want people to tender for that service later on this year: so we will be one, the out-of-hours GP service will be another, the ambulance service will probably be another. So we're in the middle of looking at what we, the model of care we would choose to implement and manage, but again that's an unknown quantity … because one of the issues is 'Will that just be open to everyone, will it be a free for all?'" [Commissioning PCO: Hospital manager]

Although Commissioning PCO was not subject to a merger, it did carry out substantial reconfiguration with the aim of developing locality-based structures that would be more appropriate for PBC. This internal restructuring led to several months during which respiratory commissioning was largely at a standstill. PCO staff who had previously been leading on the respiratory service left or were moved into new positions and the respiratory CRG did not meet for several months. This meant that management and support of the community respiratory team, which had come from the PCO and the CRG, fell away. The relationships between the community respiratory team and the consultants remained a source of support however.

In summary, the strong collegial relationships between the respiratory consultants and the community specialist respiratory nurses, built up over some time prior to the introduction of the service, contributed to the viability of the team. Less positively, the close association with secondary care may have contributed to the situation where few GPs (apart from limited engagement of PBC leads) were involved in developing the service through the CRG and some were not yet using the service.

Where are the GPs?

The relationship between local GPs and the community respiratory team seemed very mixed. Only five of the 70 people who attended the service launch meeting were GPs. The CRG which provided clinical input to the PCO's development of the service was chaired by the consultant, Dr Collins and it appears that provision was not made for locum fees to be paid to enable GPs to attend. In addition to being a practical deterrent to attending, this may have implied to GPs that their input was not valued.

Some GPs strongly supported the service, though interestingly this was in part based on a long-standing relationship with Sister Christie:

"I think one of the reasons why the respiratory [service] has worked so well is because the people who are running it, [Sister Christie] who runs it is very, very good and has been around for a long while and knows us all and is really well motivated to try and get it working and there are some very good nurses and physios involved in it and it's very effective, they communicate extremely well with us and frequently, perhaps more frequently than we'd like, but it is very good, you know exactly what's going on"   [Commissioning PCO: GP]

Other GPs did refer patients to the service but felt less actively involved with it. One GP commented on the differences between the community

respiratory team and the regular face-to-face contact with the multi-disciplinary team for terminal care:

> *"It's [the community respiratory service] a slightly faceless service to us so far I'd say…these things always work better when you've got face to face contact, you know, what can be done on a side of A4 can be said in a sentence pretty much and it gives a better sense of continuity I think and a better sense that everybody's working for the same team. It gets a little bit frustrating at times if you get instructed through a fax to do something"* [Commissioning PCO: GP]

There were GPs who actively resisted the service because they were not convinced of the need for the community respiratory service and challenged the evidence that it reduced emergency admissions to acute care. They were also wary of PCO attempts to move work from secondary to primary care and the associated increase in workloads for GPs. GPs who used the service, however, valued it precisely because it eased their work with respiratory patients as they were largely managed within the team.

GP resistance thus seemed associated with lack of awareness. Interviewees most involved with the service suggested that all GPs should well be aware of the team's existence and way of operating, as it had been widely publicised through written material and had been discussed on several occasions at protected learning time sessions for GPs. It is also possible that there was confusion about the role of the service. When the service was first introduced, patients were referred to the nursing team from secondary care only (the aim being to manage the workload carefully in the early stages) and referrals direct from GPs were only encouraged later (at which stage all GPs were sent written material describing the service and inviting referrals). There was also confusion about the scope of the service being provided by the team: although the team was called the chronic respiratory disease service from the outset, its main focus initially was on patients with COPD and this led to some irritation and confusion over inappropriate referrals.

Practice-Based Commissioning

A GP involved in PBC commented that he saw PBC as a way to break down traditional barriers between managers and clinicians and an opportunity for GPs to influence local services, though he did not think that all of his GP colleagues were aware of this potential or shared that view:

> *"…I think there's a central message that's not getting through: that this is the first time that we can influence our referring environment. Whether Practice-Based Commissioning works or not is another thing, but I think if we can start getting these dialogues going on you've got a format for breaking down those barriers with, traditional barriers with management. Clinicians feeling alienated towards it, not involved, and I think in [town] they're making a real big effort to get clinicians involved, and not in just a superficial way."* [Commissioning PCO: GP involved in PBC]

The community respiratory service was in due course adopted by one of the three local PBC groups. PBC Groups tended to adopt 'ready-made' projects set up by the PCO (such as the respiratory service) rather than taking the lead in designing new services:

"So we had this problem where there's a lot of strategic stuff going on from the PCO which is already bringing out services from the hospital so they were a little bit ahead of the game I think compared to many PCOs around the country. And then as a small locality what do you do…do we ignore these major strategic things going on? Do we say 'Look, let's get involved and start trying to influence it a bit because it's where the big gains are financially – big gains stopping people going in to hospital'. So we thought 'Well, that's OK. We're a small group here and none of us have the time to start redesigning ways of saving money, we're reliant on the commissioners anyway and the information they're going to give us'". [Commissioning PCO: GP involved in PBC]

Several practices refused to take part in PBC, and adoption of the respiratory service may even have influenced these GPs against the service.:

"We have the most cynical bunch of GPs which, you know, it kind of keeps you grounded, … they're just not budging and I suspect that if they don't know about it [the community respiratory team] it's because they've discarded it as part of the Practice-Based Commissioning thing, I don't know what to do about that." [Commissioning PCO: GP involved in PBC]

The internal reorganisation of the PCO also impacted on the PBC groups' work:

"…with all the reshuffle of the PCOs and things so our commissioners have changed, which means it's caused a little bit of chaos…people who were leading on projects in January now aren't, they've moved into a period of transition so things have gone quite quiet…It doesn't really inspire wanting to do a lot of work with somebody [at the PCO] knowing they're not going to be there in two months time." [Commissioning PCO: GP]

6.8.5 Summary: The three themes in Commissioning PCO

Professional boundaries

The development of the community respiratory service revolved around relationships between Commissioning PCO, respiratory consultants and the specialist respiratory nurse leading the team. A history of close working relationships between hospital respiratory consultants and the lead nurse sustained the service through PCO reorganisation, when support and management fell away. These relationships also helped overcome the potential disruption of the mentoring arrangements when these were questioned on the grounds of governance issues managed across two different trusts. GPs engagement with the service remained patchy. The

service as a territory shaped by hospital and PCO interests went uncontested by primary care.

Change

The service was not affected by the mergers of neighbouring PCOs or the planned reorganisation of secondary care services. However, the PCO underwent internal reorganisation to align with the need to develop PBC, which reduced support for the respiratory service at a time when referrals were increasing following advertising to GPs. The result was that further development of the services was curtailed.

Commissioning and markets

This case illustrates the impact of a more formalised commissioning process on service developments. The establishment of the community respiratory service was a structured and orderly process, initiated and controlled by the PCO, something which contributed to its sustainability through recurrent funding. On the other hand, the consequent emphasis on performance management resulted in a focus on COPD admission prevention to the detriment of other activities, such as provision of oxygen assessment and professional training.

6.9 Rural PCO

6.9.1 The Service setting

Demography

The PCO covers a large, sparsely populated, mainly rural area with poor transport links. Compared with England and Wales as a whole, the area has a higher proportion of the older age groups, both working and retired, and a lower proportion of young adults. Levels of deprivation are lower than elsewhere in the country; the poorest areas are a few pockets within urban centres.

PCO reorganisation

The PCO currently both commissions and provides services, although it is unclear whether it will continue to do so. In the interim, more formal arrangements for commissioning from its provider arm are being set up.

Reconfiguration of neighbouring PCOs and the hospital services located within those areas is pending and will affect referral pathways from Rural PCO.

The PCO has a large financial deficit and has had substantial political difficulties leading to adverse publicity, external review and changes in senior personnel. These issues are being addressed and by the end of the case study, the PCO had entered a more stable period. However, there remained particular difficulties in the commissioning budget, and it seems likely that substantial service reorganisation will be needed.

Organisation of respiratory care

There are around 20 GP practices, many operating from a number of branch surgeries.

There is no single Hospital Trust to which the PCO can relate. Secondary care services are provided by a number of hospital trusts located in neighbouring PCOs, although in practice the majority of patients are referred to around eight of them.

The PCO also has a network of community hospitals, which provide inpatient beds for respiratory patients (on general wards) and outpatient clinics. A respiratory consultant from one of the neighbouring hospital trusts runs outpatient respiratory clinics in two of these community hospitals. Rationalisation has placed some of these hospitals under threat of closure, which has prompted considerable community activity by patients and health professionals in support of 'their' local service.

There is a specialist respiratory nurse, based in the west of the PCO area, who provides a clinical service for some local patients, and education and training for primary care staff (GPs and nurses) and community staff.

6.9.2 The story of Reconfiguration of Respiratory Services

Table 13.   Chronological overview of key events in Rural PCO

Date	Development
Pre-2003	A community specialist respiratory nurse (Sister Roberts) located in the west of the PCO area was appointed to provide a diagnostic and management service for local GPs with the aim of reducing admissions, and providing an education programme for community and practice staff.
2004	A PCO management appointment to address the nursing requirements of managing LTCs did not work and the post-holder left after two years.
2005	Plans were developed for a second specialist respiratory nurse, to work in the east of the PCO area. The post was advertised and candidates interviewed, but no appointment was made. The post was subsequently frozen to alleviate the financial situation, putting pressure on many development plans.
	A strategy was developed to provide a respiratory service using existing workforce resources. Accredited training was *"bought in"* for interested practice and community staff. The specialist respiratory nurse provided support, education and some 'outreach' work.
2006	The specialist respiratory nurse and PCO managers contributed to the development of a regional COPD care pathway, including a self-management component for early implementation.
	The PCO mapped the skills and existing LTC services.
2007	Charitable funding was secured for a two-year community-based specialist respiratory nurse post, to provide a strategic and educational role in the east of the county with the post to be funded by the PCO thereafter.
	The PCO's primary care and community care directorates were combined to strengthen the management of LTCs' services.

6.9.3 A fuller story

Prior to 2003, a community specialist respiratory nurse (Sister Roberts) was appointed to a post based in the far west of the PCO. GPs, aware of the high concentration of patients with occupational respiratory disease and concerned about the limited services available, pushed for this appointment. The remit was to provide a diagnostic and management service for local GPs with the aim of reducing admissions and education for community and general practice staff.

In 2004, a managerial post was created at the PCO to co-ordinate services for the care of people with LTCs. The aim of this post was to enable the PCO's service managers to link local care teams (district nursing, occupational therapists, physiotherapists etc) and provide a strategic approach which had previously been missing. The post-holder also managed the specialist nurses. However, a combination of factors (e.g. the wide remit, the local geography, the need to work with multiple different organisations with different policies and procedures) made the role very difficult and the post-holder left after two years.

In 2005, candidates were interviewed for a second specialist respiratory nurse in the east of the area, but no appointment was made. The post was frozen because of the PCO's financial situation, and a strategy developed to provide services using existing workforce resources. Accredited respiratory training was *"bought in"* and offered to interested practice and community staff. The existing specialist respiratory nurse provided support, education and some 'outreach' work, albeit limited by the large rural location.

Two development projects were undertaken in 2006: the development of a regional COPD pathway and a mapping project to assess the existing skills within health and social care services in LTC management.

The PCO manager for LTCs left at the end of 2006 and the post was subsequently frozen for financial reasons and abolished several months later. Aspects of the role (e.g. the management of specialist nurses) had to be absorbed by other PCO managers; the resulting increase in workload meant that several development plans stalled and the PCO were unable to make full use of the findings from this mapping project.

In 2007, as the first phase of a 'link-nurse' initiative, Sister Roberts provided ongoing training and support for 11 COPD-trained district nurses in the north of the area. The aim was that there would be a strong network of interested nurses and pharmacists to support primary care management of more complex respiratory cases.

Later in 2007, funding was secured from a respiratory charity for a two-year post for a specialist respiratory nurse to work in the east of the PCO area. The PCO agreed to provide on-going funding once the initial two-year period has elapsed. The intention was that this post-holder's role would be primarily strategic and educational and that they would work with social care services, voluntary organisations and health services to develop an integrated approach to COPD care.

Other initiatives in 2007 included a trial of hand-held electronic devices for district nurses and specialist nurses to enable the synchronous sharing of clinical data with GPs, and plans to roll out the self-management component of the new COPD pathway. Clinical partnership networks with the main hospital providers reviewed patient pathways to determine the shape of services within and outside the PCO boundaries. In December 2007, the PCO combined its primary care and community care directorates in order to improve internal communication and strengthen the focus on LTC management.

In addition to these developments, many interviewees in Rural PCO believed that the introduction of the QOF within the GP contract had made a considerable difference to general practice respiratory care, encouraging GPs to improve the accuracy of disease registers and to review proactively the care of more complex patients.

The future

The PCO recognised that improvements were needed in management of LTCs and intended to prioritise this area in the near future, but was hampered by the continuing weak financial position and the consequent reorganisation. There was also concern that major reorganisation of neighbouring hospital services might adversely affect access to secondary care services for patients from the Rural PCO. The recent appointment of a charity-funded specialist respiratory nurse to work in the east of the area with a primarily educational and strategic role should strengthen the service for respiratory patients, though further resources will be needed.

6.9.4 Key features of the development of respiratory services in Rural PCO

Respiratory services in Rural PCO changed little over the course of the case study. Instead we observed factors that were influencing how existing services were provided and affecting efforts to change services.

A strong feature of this case study was the absence of a GP with an active interest in developing respiratory services. Several interviewees alluded to the existence of a GP in the area who was particularly interested in respiratory care, but no-one was able to give this person's name or location. One GP, whose respiratory interest was listed on the practice website, was unable to participate in the study because of the pressure of staffing problems in her practice. Thus, in contrast to Merged PCO and Team PCO, there was no GP actively engaged in change in respiratory services locally. Several interviewees, including the specialist respiratory nurse who seemed somewhat isolated in championing respiratory care, commented that respiratory services had a low profile locally:

> *"Well there is no service basically. I mean there is no equality of care throughout: patients that have direct contact with me no longer want to go back into the system. What they're saying is that within the GP practices all they get is spirometry for the [QOF] points which is hard going. To do spirometry on somebody that can't breathe is a hard test*

to do…so there is a very poor almost non-existent service within [Rural PCO] for respiratory disease. You know, cardiac, diabetes, even incontinence have all got teams of nurses, palliative care and respiratory is just, to my mind [Rural PCO] pays lip service to it". [Rural PCO: Community specialist respiratory nurse]

"[Rural PCO] is as bereft of a respiratory strategy as it ever was". [Rural PCO: Respiratory consultant]

"[Respiratory services] is one of those [areas] that [Rural PCO] considers it could do more [for]." [Rural PCO: PCO manager]

Another strong feature of this case was the relationship between primary and secondary care. The rural/remote geography and absence of hospital services within the PCO appeared to have resulted in an emphasis on developing services within primary care, and many GPs were comparatively independent and autonomous because of the distance between them and the nearest hospital. The referral threshold to secondary care was high and GPs appeared to occupy some of the 'space' that in other areas might have been taken by intermediate or secondary care:

"I think the issue is that because we haven't got a DGH, one DGH, and because we haven't got, if you like, a hungry developing acute provider which seems to pull patients in, we have been able to empower primary care more to be able to do the work. I think the other thing is we've got very high quality general practice - always have done. They've worked with the community hospitals over the years, they've provided a very high quality of primary care, we've got a very high quality of nurses who work in primary care and I think that that comes with the rural community." [Rural PCO: PCO manager]

Interviewees gave a strong impression that GPs had become used to working independently and that they recognised that respiratory services had to be provided locally:

"The other problem is that we got used to having a fairly strained respiratory system in that, until recently, there was only one respiratory physician, so there was a long waiting time for referrals. Patients were bounced back to us very rapidly and we had to have a high level of input for our respiratory patients, plus if we referred them in for pulmonary rehab or to have sessions with the respiratory specialist nurses that involved up to an 80 mile round trip and so for a lot of our patients that just wasn't going to be the case. So we have things like the Macmillan Easy-Breathe Programme and quite a lot of educational resources solely because accessing that stuff in secondary care is really hard for patients." [Rural PCO: GP]

Relationships between GPs and the respiratory consultants appeared to be cordial and supportive, albeit geographically distant. There was more direct contact in the east of the county, where a consultant from one of the main referral hospitals provided outreach clinics in two community hospitals, and was seen as a key figure in inspiring respiratory service development around that hospital and providing a 'vision' of how services might develop

in Rural PCO. She worked locally with the GPs, practice nurses and district nurses and the staff in the local community hospitals, and acknowledged that the relationship between her and the GPs was affected by the rurality of the area:

> Interviewee: *"And, you know, like you've come across rural areas where people, GPs and GP practices have a certain degree of independence because they're independent characters I think and so it would be difficult to claim that all practices in [area] or [area] behaved in the same way."*
>
> Interviewer: *"So you feel there are differences in the way that…?"*
>
> Interviewee: *"Well there are and I think that you have to accept that and then support within that sort of difficulty if you like. You know I think we need to know what the GPs want of it. I mean I must say I try and encourage it not to be dictatorial from the top but to sort of introduce yourselves to GPs and say 'What can we do for you to help you manage your patients with COPD?'"* [Rural PCO: Respiratory consultant]

This relative independence of GPs and their ready contact with consultants seemed to affect attitudes towards potential new roles such as GPwSI. The PCO had decided against a GPwSI-led service, in part because their human resources department had advised that this was a more complex contractual arrangement than existing roles (e.g. clinical assistant or hospital practitioner), but also because they had not identified a clear local need for this role. Instead, local enhanced services were used to address needs:

> *"…and [the PCO] have developed a lot of, far more local enhanced services within the new contract framework compared with many other areas, so they do appreciate the nature of the rurality. And of course we haven't got a district general hospital in [Rural PCO] so really there's an appreciation that services need to be community based really."* [Rural PCO: GP]
>
> *"And I think that's maybe meant that the need to build those specialist roles…if you look at the ones who have got a special interest they're GPs that have come into [Rural PCO] with that interest, so they've built it up somewhere else and I just think it could be about the way [Rural PCO] works with its network of district generals, as I say I suppose it's because [Rural PCO] doesn't have a district general of its own, there's access to all these others."* [Rural PCO: PCO manager]

Equally, there seemed to be little interest among GPs for a GPwSI role:

> *"I don't think I'd refer many people to them to be honest with you, I'd prefer a consultant because you can get hold of consultants. I mean I suppose their role would probably be more working with a consultant in clinic and offering long term follow up to people."* [Rural PCO: GP]
>
> *"…my partner used to do clinics with the local [consultant in diabetes] and he used to consult separately, I'm sure he used to tell him about the patients and then he used to sort of make sure he was doing all the right*

things and that's the sort of model I think if they were going to work they would work best in." [Rural PCO: GP]

Indeed, one GP explicitly stated that he did not want the PCO to provide a separate service but instead to provide him with the resources to develop his existing staff across his multi-site practice:

"I'm not sure that I want a PCO or a secondary care service to provide me with a facility to access. What I really want them to do is to give me resources so that I can train the staff that I already have and that are in place in my buildings to provide the service for the patient close to their homes. And that's the bit that doesn't seem to happen really as easily as it might, you know, so people in the PCO sit there and think 'oh, you know, we've got to provide this service, we'll organise this service and then they can send their patients to there so we'll set up a hospital clinic or we'll set up something' – we don't want it, just give us the money and we'll actually spend it in the right way." [Rural PCO: GP]

What appeared to have been a major driver for change prior to and during the case study period was the introduction of QOF, which many GP and manager interviewees described as having provided considerable impetus to systematising the care that practices offered:

"...the change over the first three years of QOF in the compliance with COPD and asthma is tremendous. The number of patients who are, in COPD terms, being now properly looked at, properly dealt with, have got their FEV_1s (Forced expiratory volume in one second) done regularly, they're being very positively managed...what the practices are telling us is that this is the group of patients they've seen the most health gain in." [Rural PCO: PCO clinical manager]

"Well I think with the new contract we've got much more organised in actually running the COPD much more tightly and the spirometry in actually making sure that there is a pro-active [management] plan whereas before I think you tended to be reactive towards the treatment...I think QOF actually galvanised us into a more structured follow up for all these patients...I think the QOF has been good for respiratory patients actually...Yeah I mean I think we were getting there but I think it made us get there much quicker." [Rural PCO: Two GPs from same practice]

The PCO carried out a systematic programme of visits to monitor QOF measures and to tackle deficits; indeed some practices described this as their only link with the PCO, but it was clearly taken very seriously by practices and the PCO:

"...what we've found in general practice is that by introducing the COPD registers and by being very strict on general practitioners on the achievement of regular testing of these patients, regular input into the review of all those patients, that actually across all of the primary care teams we've seen a decrease in the number of patients admitted to secondary care." [Rural PCO: PCO clinical manager]

By contrast, however, some interviewees thought that QOF had led to 'box ticking' rather than necessarily to improved patient care, particularly for patients with more severe respiratory conditions.

Another, lesser driver for change in respiratory services in Rural PCO was a change in national arrangements for oxygen procurement, with some targeted money. A review of long-term oxygen use was already underway, identifying that the service was poorly organised with potential financial and clinical improvements.

In addition, several local initiatives were developed by clinicians and managers to try to improve respiratory services, but these had been hampered by a range of factors. Four initiatives are described here: the appointment of a community specialist respiratory nurse, the appointment of a manager to lead on LTCs across the PCO; work to develop a COPD pathway; and a project to map existing skills across the health and social care workforce.

Community specialist respiratory nurse

The community specialist respiratory nurse appointed in the west of the PCO some years before the study began had been hindered in her efforts to improve respiratory care across the area by several factors. There was a lack of awareness of the service, and some nurse interviewees were unaware that the PCO had a community specialist respiratory nurse. The clinical workload was heavy but the nurse felt unable to concentrate on education because of her concerns about the quality of care amongst practices:

> *"…when I first started, I would see 300 or 400 people…they want me to move away from it [patient contact] and become more of a resource to the GP practices. The problem is, they're not doing the work, the GP practices and the community nurses and the hospitals to a certain extent are not doing what needs to be done."* [Rural PCO: Community specialist respiratory nurse]

In addition, when she provided education programmes, she was frustrated that the teaching was not always retained:

> *"I would perhaps do around a 6 month run of basic stuff, really basic stuff to get people just to think about the conditions and the medications and really basic things like that, and then I come along a year later and I'm still having to do the basic stuff because it won't have been retained."* [Rural PCO: Community specialist respiratory nurse]

The large area and long travelling times made it difficult to maintain regular contact with practices across the whole area and she concentrated her efforts in the west of the PCO area. An attempt to set up a PCO-wide network of respiratory link nurses had proved impossible because of the size of the area. She had therefore concentrated on establishing a link nurse network in one of three sectors before extending the network into other two sectors. Plans to recruit a second community specialist respiratory nurse, to cover the eastern end of the patch, had come to nothing, which was

described by interviewees as *"a real blow"*: it had not been possible to recruit to the post and then before efforts could be made to re-advertise the post, the post was frozen permanently because of the PCO's financial problems.

The specialist respiratory nurse also faced difficulties in establishing her status in relation to other health professionals, especially GPs, who after initially being sceptical of her specialist credentials then overwhelmed her with referrals, consultants who denied her the authority to refer, and nursing colleagues who were suspicious of her role:

> *"Every time, every single time, .. every practice you go into, they feel very threatened by specialist nurses, they feel that you're going to go in there and criticise their practices and usually the way I get into the GP practices is the community nurses will refer a patient directly to me, ...and I will go in and see that patient and then I will write a comprehensive report back to the GP and suddenly they go 'Oh maybe she does know a little bit of what she's doing then', and then next thing you know I'm getting bombarded with 'Well actually this one's a problem and that one's a problem and can you do this and can you do that?', so you've got to be very careful because they will get you to do their QOF work for them."* [Rural PCO: Respiratory specialist nurse]

> *"It's [teaching GPs] a very difficult thing to do...You only need to get one obstructive or difficult person within the group and they can make it very, very difficult. I mean some of them are absolutely wonderful and they'll invite you in time and time again...But any specialist nurse teaching a GP will always...I mean some of my other colleagues that I've spoken to they all feel the same way, you know, it can be very difficult...."* [Rural PCO: Community specialist respiratory nurse]

> *"It depends on which [hospital]...some consultants will take direct referrals others won't, so like [names of hospitals] will take direct referrals from me, the others I have to go through a GP, so it's all to do with status."* [Rural PCO: Community specialist respiratory nurse]

> *"...the radiographers won't take a direct referral from a specialist nurse... just to get a simple chest x-ray is like climbing Mount Everest. They are so resistant to specialist nurses referring, ..They won't even take a recommendation, so if I rang a GP and said 'Look, I've seen this chap, this, you know, this is the situation, he really needs a chest x-ray' the GP will go 'Right, OK, I'll do the form then', they won't accept that either, the patient has to be seen by the GP, so it extends the patients journey which is so frustrating...if the patient's housebound, it means a GP visit, if they're not it means they have to struggle up to the surgeries and then they have to struggle back down here or wherever they are going for the x-rays, very difficult."* [Rural PCO: Community specialist respiratory nurse]

PCO manager for long-term conditions

The appointment of a lead manager for LTCs took place prior to the case study period but was described by interviewees in the study. It had been

intended to act as a focus for improving the care of patients with respiratory and other conditions but the post-holder was reported to have struggled with the geographical constraints, the size of the remit and conflicts over the role. When the post-holder left, the post was abolished. The subsequent increase in workload for the remaining clinicians and managers working in this area meant that a number of service plans were put on hold, while individuals concentrated on 'fire-fighting' and further staff were lost due to ill health.

Development of a COPD pathway

The community specialist respiratory nurse and PCO managers contributed to the development of a regional COPD care pathway. However, they described difficulties in recruiting a local practice to pilot the pathway:

"The unfortunate thing is we couldn't get them on board in the developmental stage of the planning…they just seem to be a little bit apathetic really, I think it was very much a case of 'Well, you do it and we'll decide at the end of it' you know." [Rural PCO: Community specialist respiratory nurse]

Project to map the skills of staff working in long-term conditions

This mapping project aimed to map the current profile of services; to provide a baseline assessment of the skills available to local care teams to support patients with LTCs; to make recommendations on the skills needed; and to influence organisational strategy for LTCs. Staff were asked to indicate the number of patients they had seen with LTCs in the past six months and what other needs they thought should be addressed (i.e. the wider determinants of health). One of the aims was to educate the PCO's commissioners about the role of specialist nurses locally:

"…profiling their roles and what they're involved in just so that we can inform commissioners about the length and breadth of the role really, you know, that it's not just about the numbers you see on paper, how many patients seen, you know, so we want to use things like patient stories, we're also going to use a satisfaction questionnaire which we'll use across all the specialties." [Rural PCO: PCO manager]

However, workload pressure, financial difficulties and political upheaval at the PCO prevented implementation of the findings in terms of addressing service configuration and staff training needs.

The organisational context

Rural PCO was working in a context of considerable uncertainty and upheaval. It had a substantial financial deficit, which had an adverse effect on service development. Interviewees felt *"overwhelmed"* by the policy agenda and by frequent changes of direction:

"Brace ourselves again, but I mean, you know, I think on the one hand, you know, we're all desperately wanting some period of stability because there's been so many policy documents and, you know, it's just, it's

overwhelming at times, ….it's not sustainable the health service and how it's currently being delivered and I guess probably we do need radical change but then please we need a period of consolidation." [Rural PCO: PCO manager]

Because GPs in Rural PCO referred patients to hospital trusts based in a number of neighbouring areas, the PCO had to keep a 'watching brief' on, and seek to be actively involved in, the reconfiguration plans of those PCOs, adding another level of complexity:

"There are two things happening I suppose that quite significantly affect us. [Hospital Trust] are looking at centralising their core services at a site much further away from us…But what we have to make sure in both of these areas is that we're in there and we know what discussions are going on and we remind people that it's actually going to affect [Rural PCO] residents as well because we don't have our own DGH." [Rural PCO: PCO manager]

This uncertainty about external services was added to concerns about threatened service rationalisation within the PCO. Prior to the study, plans for substantial changes including the closure of some small community hospitals had provoked considerable community protest, following which the plans had been referred for further consultation. Interviewees described how many staff felt torn between their professional beliefs and their personal experience of living in the communities affected. The opposition of many GPs to the PCO's plans and to what they perceived as a lack of appropriate negotiation had damaged the relationship between the PCO and GPs, although efforts were being made to repair these relationships:

"So what we're trying to do is see if we can start the sort of meaningful dialogue with the PCO again…One of the problems before was they didn't really engage with the clinicians on their kind of proposed changes…I mean it didn't seem to be a particularly well managed engagement and sort of exploratory process beforehand when they were actually coming up with the plan for their reconfiguration, I mean to the stage where I went down to see the [government minister] with a couple of my GP colleagues." [Rural PCO: GP]

Changes at chief executive level were contributing to uncertainty and led to inertia as decisions were delayed hold until the new post-holder arrived:

"We've lost and gained a new chief exec as well…at grassroots level nothing has changed at the moment but I mean you're always living with this background fear of 'we don't know what's going to happen.' I mean we don't know if this new person coming in is going to come in and do, make sweeping changes or whether he's going to sit back and, because it's only an interim post at the moment…So really, you know, you can't, decisions are not being made at the moment, you know, if you're waiting for things to happen, particularly if there's a financial implication, you know, so it's all very unsettled." [Rural PCO: Community specialist respiratory nurse]

The PCO was undergoing an external review related to clinical governance concerns, including the debate about whether the PCO could continue to be both provider and commissioner of services: *"We've had a clinical governance review recently which has, well made it, really made it clear that there isn't the expertise and ability within the [PCO] to manage the commissioning of services."* [PCO manager] However, in contrast to the other three case studies, implementation of PBC was not an issue locally, and was, therefore, not a factor influencing respiratory service development.

6.9.5 Summary: The three themes in Rural PCO

Professional boundaries

Professional boundaries had most impact in this case in relation to the community specialist respiratory nurse: her status as a nurse limited what she was able to do. There was no contest over respiratory services between the hospital sector and GPs: the hospitals were all located outside Rural PCO and because of the distances to secondary care services, GPs appeared to be relatively autonomous and to have been occupying for many years an intermediate 'space' between primary and hospital services.

Change

Service development was affected by the PCO's financial deficit and changes at senior level and by uncertainty about the future of local services, both in relation to community hospitals within the PCO area and to secondary care hospitals in the neighbouring areas where hospital services were being reorganised.

Commissioning and markets

At the time of the case study the PCO was both commissioner and provider but more formal arrangements were being introduced to separate the two functions and it was unclear how future arrangements would impact on service development. Service development in this case was unaffected by PBC as this was not being implemented in the area.

6.10 Themes across cases

Following the presentation of each single case, we now turn to a comparison across all four cases in terms of the three themes: change, commissioning and markets and professional boundaries. This comparison is made with reference to the literature as a basis for some theoretical generalisation from our case material.

Exploration of the in-depth case studies centred around questions about the formation of service development 'teams':

- What factors determined involvement of key players in service development?

- How did context shape alignment or competition between interests?

- What impact did negotiation of interests have on service arrangements and the formation of new roles?

We also compared the GPwSI and specialist nurses' roles in order to understand the GPwSI role in context and derive broader issues in workforce change

6.10.1 Change

"We have all these strands, we've got 18 weeks, we've got Practice-Based Commissioning, we've got Choose & Book, we've got other things that are happening, we've got the financial recovery planning, all going forward in parallel but it does all cross-cut, the patient is somewhere in the middle of all of this, we've got PCOs trying to, yes, recover the financial position but we've got Practice-Based Commissioners and GP practices who are looking to see how they can free up resources to put into their pockets. You know, how many of these plates can we keep spinning all at the same time and if we drop one what is the impact on everything else?...and we've all got this anxiety hanging over our heads, 'Well will I have a job in a few months time or six months time?', so I think that there is a huge pressure on at the moment." [Merged PCO: PCO manager]

The case studies were conducted during a period of significant turbulence and organisational change, and in all four settings the most striking feature was the lack of stability. Interviewees in each of the four case study areas were dealing with a range of challenges that made it harder to provide existing services or to develop new ones because of uncertainty about the shape of future services, conflicting policies, changes in personnel and loss of contacts through which service provision and development work were previously conducted.

Although organisational change is an enduring feature of complex organisations like the NHS, many authors (e.g. (Ferlie, 2004; Walshe, 2005) agree that the period since 1997 when the Labour government took office has seen unprecedented change in the NHS in terms of its scale and scope: *"what appears to be the largest and most expansive set of reforms, structural changes and investments in infrastructure in NHS history"* (Leatherman and Sutherland, 2003) and that there are few signs that the process is slowing down:

"A formidable torrent of pledges, policy documents, laws, regulations, advice and guidance has issued from the Department of Health, without let-up since 1997, to knock the system into shape: ironing out disparities, raising standards, improving productivity, increasing responsiveness, extending services, meeting unmet needs" (Appleby and Coote, 2002)

"A pattern of hyper-reforming continues" (Ferlie, 2004)

Evidence suggests that such organisational turbulence has an adverse effect on clinicians and managers working in the NHS: 'change fatigue' and a 'wait and see' approach to national initiatives have been documented (Cortvriend,

2004; Fitzgerald et al, 2006; Garside, 1998; Leatherman and Sutherland, 2003; McKee et al, 1998; Smith et al, 2001). Wide reaching change reduces employees' motivation to engage with new initiatives (Schalk and van Dijk, 2005). In particular, it is well documented that mergers substantially disrupt service provision and development. For example, Fulop and colleagues, in a study of the processes involved in and impact of mergers between NHS trusts, observed a negative effect on service delivery because of loss of managerial focus, delaying developments by at least 18 months (Fulop et al, 2002). They concluded that important unintended consequences should be anticipated when mergers are planned, and greater management support provided. They warn that plans for future organisational restructuring, including in primary care organisations and in health authorities, need to take these considerations into account.

Although the over-riding impact of change in our case study PCOs was, at the time of data collection, disruption, change also produced opportunities for service development and strategic change. For example the commissioner in Merged PCO grasped the opportunity to extend the GPwSI services throughout the county.

6.10.2 Commissioning and markets

Mergers and commissioning

A key rationale for the 2006 PCO re-organisation was to strengthen the primary care-driven commissioning, by creating larger and stronger commissioning departments (Department of Health, 2005a; Department of Health, 2006b) and supporting PBC which aims to bring commissioning decisions out to clinicians (Department of Health, 2004e). At the time of our study, which was during the early stages of the change process, the turbulence following the reorganisation was having the opposite of the desired effect: the commissioning process was weakened rather than strengthened.

Implementation of the new structures and processes was at an early stage in three of the case study PCOs (the exception was Commissioning PCO), and many clinicians and managers were confused about developments, as this typical comment illustrates:

Interviewer: "and in terms of the way that the PCO goes about making decisions on funding one initiative or another, do you think those processes are transparent to people who want to put forward a proposal of one kind or another?"

GPwSI: "It's a complete mystery. I mean, we don't know how the decision was made to fund our project at all. I mean…one of the problems is that they make decisions, I think they make decisions because they think it is a good idea and they don't kind of think about things and that's why, you know prior to the merger you had all sorts of different weird initiatives going on in all these different PCOs with no kind of co-operation with primary care services and no consultation. And I think with the new PCO I think there'll be better financial planning

because I think they have got rid of some of the people who were perhaps less than brilliant. But certainly, there hasn't been any consultation with our GP colleagues about setting up this [new Merged PCO-wide service]." [Merged PCO: Coastal PCO GPwSI]

Even in Commissioning PCO, which was the furthest advanced in terms of its commissioning arrangements, there was confusion:

"I mean the GPs at the respiratory team said, when we brought it [commissioning a community respiratory consultant] up last time and there was nobody from the PCO so we couldn't go anywhere with it, .. It's part of a turnaround plan for the PCO, but there's nobody here to answer that question because Mr. Chapman, who was supposed to be doing it, has moved on and now there isn't anybody there to do it, so we'll have to put that one off for the next meeting. There's somebody from the regional [health authority] for six months who's covering that role but that time is almost up and we haven't had a meeting yet. So it doesn't really inspire wanting to do a lot of work with somebody knowing they won't be there in two months time." [Commissioning PCO: GP member of PBC group]

This was exacerbated by the emphasis on contestability and the presence of private providers in the area, and the instability due to reconfiguration of PCO managers :

"It was quite difficult you know, with all the changes that had gone on, whereas before we worked much more as a partnership with the University Hospital, you know, from a commissioning basis. Now…there has been this talk about new providers and…in many ways our relationship has become more difficult…there is more conflict of interest and things like that, so sometimes I just stay out of it." [Commissioning PCO: PCO manager]

Practice-Based Commissioning

The structures and processes for PBC were embryonic, with widespread lack of knowledge, understanding and engagement, particularly amongst clinicians, and limited resource within PCOs to develop the system. Unsurprisingly, therefore, PBC had limited impact at the time of our study, though in both Team and Merged PCOs adoption by the PBC group of the respiratory services was a significant step.

"That's right, when we heard that there was a [PBC Committee at the PCO] it was a great surprise to us. I'm sure most of my colleagues don't even know that there is one. Because up until that time all the [area] umbrella groups PBC meetings had representatives of the PCO who were at a very junior level. There had been no representation at all, much to the frustration of the groups who were trying to make decisions in the area of commissioning which would have a significant impact on resources and use of resources and not a single director ever came…and I was attending this meeting clearly by chance when we discovered there was something called a PBC committee with a Director or two on it and it

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was the first thing we had ever heard of it and communication has not been the best." [Merged PCO: GP]

In Merged PCO the GPs were beginning to be proactive, forming a consortium in response to poor relationships between GPs and the PCO and as a way to protect GPs' interests in the face of competition from other providers, though this was hindered by the lack of transparency in the PCO's tendering process:

"I mean last thing – what they're actually up to at the moment in [clinical specialty] - Clinical Assessment and Treatment Centres, and they [the PBC consortium] found out very, very late on, only mid April that the PCO had put out to tender bids for...and the closing date was 10th May. So the poor things rushed off and got all the different practices all over PCO area together. But again our PCO don't exactly know how to communicate with anybody and it is a difficult and slightly strained time in my view." [Merged PCO: GP].

The PBC consortium actively resisted attempts at control from the PCO and were determined to set their own agenda

Interviewer; *"...And the strategic framework that came out from the PCO...about Practice-Based Commissioning and structures and incentives and so on, has that had any impact?"*

GP: *"It made us *** cross!...What it sought to do was to instruct us what Practice-Based Commissioning would look like and sought to take ownership completely away from us, hang Choose and Book on it – blooming useless arrangement that is – and take away all our autonomy. Wasn't best received...the group said 'I'm sorry, that's not what Practice-Based Commissioning is about, we're not here as agents of the PCO'."* [Merged PCO: GP]

By contrast, in Commissioning PCO, though PBC leads were enthusiastic about the potential benefits PBC would bring once it had been fully implemented, the PBC groups had tended to adopt PCO initiatives rather than commissioning new services:

"It's more about, Practice-Based Commissioning is approving what we do, I think they quite like what we've done so it's been more about us presenting the projects to them and then them sort of agreeing them rather than getting actively involved in developing anything new. The PCO is still leading on that, whereas in some other areas the Practice-Based Commissioners have very much taken the lead and come up with the ideas." [Commissioning PCO: PCO manager]

The finding in this study that PBC was at a very early stage of implementation reflects other research (e.g. (Audit Commission, 2007; Curry and Thorlby, 2007) that looked at the early impact of PBC across a larger number of PCOs and found limited engagement from the majority of GPs, lack of clarity about the role of PCOs in relation to PBC and little evidence that innovative service redesign had yet resulted from PBC.

Tension between commissioning and Payment by Results

Commissioning and contract arrangements sharpened the extent to which the patient represented an income (or a cost) for PCOs, GP practices or hospital trusts. Payment by Results (PbR: A national fixed tariff for emergency care, elective in-patients, day cases and outpatients), combined with increased provider competition is designed to encourage hospital trusts to increase quality and effectiveness of service in order to secure contracts (Maybin, 2007). This policy is designed to reduce waiting lists for planned care. Its impact on acute services' role in chronic disease management is however uncertain (Ham, 2008).

There was recognition that providers were *"fighting over the patient because the patient represents an income"* and that *"Practice-Based Commissioning and Payment by Results set two groups of people against each other in search for a pot of money."* [Merged PCO Hospital specialist respiratory nurse, University Hospital].

There were reports of consultants *"hanging on to patients"* (for example, seeing them for follow-ups rather than referring them to the GPwSI clinic for follow-up) in order to keep their *"patient load"* up:

> *"...we're finding the consultants like actually to keep the patients, I think that's more political than actually the need for them to keep them but we all know that if they don't have their patient load up in secondary care they don't get funding, so I think it's a big political hot-pot at the moment."* [Merged PCO: Community specialist respiratory nurse]

The timing of our study did not allow us to explore whether and how the disruption caused by tension between PBC and PbR, might resolve over time. There were signs particularly in Commissioning PCO that increased competition from private providers encouraged hospital NHS providers to co-operate with PCOs and PBC Groups in the development of local services.

"Things are becoming more business-like"

If the structures of commissioning were still in development, the overall objectives of service planning and development were becoming clearer. Demonstration of cost-effectiveness of new services was becoming more important. In all four case study areas the importance of a business plan for PCO-commissioned services increased. This needed to detail the service to be provided, with the costs and return on investments:

> *"I think we've got to perform, I mean, I feel as the manager, we have a duty to perform...the PCO is getting much more their expectation of their providers meeting their requirements, it's becoming more business-like I think...that's probably a beneficial thing in some ways, but the reality of it is actually quite difficult when you're dealing with health."* [Commissioning PCO: Community specialist respiratory nurse)

This increasing formalisation of service planning resulted in a predominant focus on proven returns on investment, almost always counted as a short-term reduction in hospital bed days. This meant that services which aimed at longer-term improvement for patients, potentially leading to reduction of

future pressure on acute care, were more difficult to establish. A specialist respiratory nurse in Merged PCO presented a case to the PCO for a pulmonary rehabilitation service, but her request was denied on cost grounds:

"I mean it's grade A evidence, if you look at NICE (National Institute for Health and Clinical Effectiveness: An independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health) *[about pulmonary rehabilitation] …but when it went to commissioning here although the evidence is very good you couldn't definitely say from the research "yes, it would save you bed days", and that's what drives the PCO at the moment [so] they couldn't finance it."* [Merged PCO: Community specialist respiratory nurse]

It could also mean that existing services, based on informal collaboration between providers within and across sectors and services, found themselves in difficulties unless they were formally commissioned and paid for by the PCO:

"When you look back now, they (specialist nurse services) weren't terribly well planned in terms of funding, commissioned services, and now there have been terrible problems within our Acute Trust, because these things weren't formally processed". [Commissioning PCO: Community specialist respiratory nurse]

"But that (sleep apnoea services) is really an extension of what we were doing before and it's not a new service from the (Hospital) Trust point of view. It's just a new way of trying to sell it to the PCO so that funding comes with it and we're not working for nothing. We can't get away with it as easily as we could in the past. Somewhere along the line some manager will say 'We're not being paid for this so we're going to stop you doing it'." [Team PCO: Respiratory consultant]

Service development was increasingly structured by the way commissioning was organised in terms of departments and budgets. This had implications for work that spanned primary and secondary care:

"I believe, and I don't know what the PCO Commissioner feels about this, but there's lots of evidence that we should be having some joint funding initiatives for posts without a doubt. I think financially at the moment we are struggling enormously and the PCO is struggling as well and so it seems to me that everyone's very protective of their budgets, which they have to be of course, but yes, joint funding might bring us more closely together and make our services more integrated in the long run I guess." [Commissioning PCO: Community specialist respiratory nurse]

The move towards an increasingly market–based organisation of the English NHS may have an adverse impact on the development of services for long term condition management. Ham (Ham, 2008) suggests that the recent reforms are designed to improve the access to planned care in the secondary care sector. Community-based management of LTCs poses

different challenges, which need to be addressed through collaboration among primary care, new specialist practitioners, and hospital clinicians. Collaboration requires a degree of flexibility, which is difficult to accommodate in a system where the details of relationships among practitioners are specified and locked in by contracts.

The longer term effects of the reforms are uncertain; they are likely to be context dependent and will require empirical investigation and research (Dunleavy and Hood, 1994). Some authors (e.g. (Hellowell, 2005; Pollock et al, 2007; Pollock and Price, 2006) have commented that the reforms are radical in their intention and scope and have suggested that the upheaval they have caused for NHS services is no accident, but instead part of a wider political agenda to increase private provision within the NHS.

We noted that, particularly in Team and Merged PCOs (in the case of Market Town and Coastal PCO GPwSI services), service developments in the pre-reform period, when commissioning was more informal and competition less marked, allowed services protected time to develop and consolidate, and to negotiate the reconfigured relationships and roles underpinning the new service. The increased emphasis on proven cost-effectiveness, the formalisation of arrangements through contracts and the impact of increased competition in the healthcare market, with a range of new providers joining the competition for tenders, may need to be monitored to ensure that fragmentation of services is avoided and that the flexible service collaboration needed for the management of LTCs can develop and consolidate.

6.10.3   Professional boundaries and personal relationships

The potential negative impact on service development of boundaries between different health professionals, between different sectors and between clinicians and managers is well recognised (e.g. (Dopson and Fitzgerald, 2005; Joss and Kogan, 1995; McNulty, 2003; Sheaff et al, 2003), and was reflected in our case studies. Our findings also suggest that the introduction of a stronger emphasis on cost-effectiveness of services, the political nature of NHS reforms, the increased competition among providers and the unstable organisational environment, introduced an additional dynamic in boundary work. Alliances between clinicians and managers, together with access to networks and relationships based on professional interest and shared work history, were important to enable clinicians to overcome these boundaries and establish new roles and territory in the intermediate sector.

Boundaries between clinicians: Arguments

Negotiations and contest were couched in debates between primary and secondary care health professionals and managers over how the intermediate services might be defined, and who were the most appropriate health professionals to provide such services. Clinicians in new specialist roles moving into the territory of intermediate care defined and justified

their position through a range of arguments, echoing Sanders and Harrison's findings from a study of negotiations of boundaries in an intermediate specialist service for heart failure patients (Sanders and Harrison, 2008).

Players used a range of criteria to argue their position including patient preferences, quality of patient care, degree of specialist expertise, avoidance of clinical risk, ability to consider the 'whole patient' and not merely the respiratory condition, cost-effectiveness, adherence to national guidelines, and alignment with DoH policy.

Secondary care clinicians argued their case in terms of expertise and patient safety:

"I think one of the concerns consultants feel is that instead of being a service whereby there's perhaps a step down between secondary care and primary care for some patients, probably most commonly for COPD, it (a GPwSI service) has been seen as an alternative to a secondary care consultation for a much larger range of respiratory conditions. Also, the way in which they have been done without the proper consultation, and particularly with what we think in taking on more than would normally be appropriate in primary care setting." [Merged PCO: Respiratory consultant University Hospital]

The GPwSIs argued for their role in relation to consultants on the grounds of alignment with policy, and their ability as generalists to offer holistic care:

"Exactly and I totally agree and I understand where they (respiratory consultants) are coming from. The point is that they cannot do otherwise now, and it's not just in respiratory, in all areas things have, are coming down to primary care because it is cheaper and more convenient for the patient anyway and they find it more convenient and better for them. We cannot really stop the progress if you like. If the government ideas change then things will change again, but for the time being the way the system is that's what we have to do". [Merged PCO: Small Town GPwSI]

"I think I have a huge advantage over secondary care physicians in that I can deliver the sort of COPD care that patients understand. And even when I worked for a very good consultant in (area) he would look at the lung function and blood gases and say 'Right, well, that's fine', and I'd say to him 'but the patient's really depressed' and he'd say 'oh, well, that doesn't matter, does it?' you know, so at least I provide a much more rounded way of looking at patients and they have quite an intensive education". (Merged PCO: Coastal GPwSI)

GPwSIs had to 'defend' their territory of 'holistic' care from similar claims by community matrons and specialist nurses:

"I think the problem is that patients need and expect to feel that they're getting the best care for their condition and...however one reassures them or whatever one says I think in the mind of the patient there is a hierarchy and nurses and community matrons are all very well for

chronic long term conditions and getting the patient up to a certain level, I think the patient can see that and is quite happy with that. But they themselves feel that if they've got some critical life threatening condition or whatever it is that they should be working with or seeing a GP or a consultant and if we want them to rather, see rather, consultants rather less often because they're so expensive, etc, then I think we've got to offer them something that is more than community matron, and I think a GPwSI is spot on really because the GPwSI can say 'Well I've got the specialist knowledge, my specialist opinion is either yes you do actually do need to go and see the consultant or actually I can look after you, I shall then, when I've stabilised your condition I shall then get the community matrons to give us extra support' and you can kind of, I don't know, filter patients more appropriately from a central core and I think the GPwSI fills that central position very well". [Merged PCO: Coastal GPwSI]

Compared to the intensity of the contest between doctors in secondary and primary care, nurses' voice when defining their expertise and role was more muted. Nurses, including community matrons, worked to establish a nursing role seen as separate from GPwSIs and consultants. In particular, community matrons, as a comparatively new profession, often felt uncomfortable with the lack of clear boundaries around their roles:

"I think it [the community matron role] will just fit whatever need there is and we'll have a core of what we can do and then we'll just fit what comes, what's thrown at us sort of thing.… It's very, very changeable, I think no day's the same, there are demands on what we, we're to do and the responsibility is actually enormous. A lot of the literature you read about the job, you know, suggests that we're junior doctors which I feel really, really uncomfortable with because I don't feel like I'm a doctor in any way, shape or form and I certainly don't ever want to be perceived as that. I'm a trained nurse and that's what I understand but I understand that I'm taking my nursing qualifications and developing them a little bit more with all my experience but I do feel uncomfortable with that 'junior doctor' role." [Merged PCO: Community matron]

Specialist respiratory nurses had to work hard to convince doctors of their clinical skills and expertise, as described by the community specialist respiratory nurse in Rural PCO. They also had to use a variety of strategies to counter resistance and at times hostility from other nurses who they felt perceived the 'specialist' title as threatening. According to the Rural PCO community specialist respiratory nurse:

"…some of the action research I've just been doing was looking at the role of the specialist nurse in relation to their colleagues and I did have quite a lot of feedback saying that they thought specialist nurses wouldn't muck in, they didn't get their hands dirt,…I've never had any problem with them personally, but I think I'm quite easy to get on with. So, and I don't, I never call myself a specialist nurse…I call myself a respiratory nurse, I never use the title specialist nurse even though it is my title I never use it unless it's on documentation which I have to use it

for that and unless I really think that it will have a bit of pull behind it if I'm wanting, if I think that a title will help my cause I will use it then, but most of the time I don't ever call myself a specialist nurse." [Rural PCO: Community specialist respiratory nurse]

The fluidity of roles made it difficult for specialist nurses to demarcate their territory in relation to both medical roles and other nursing roles (Witz, 1992). Both specialist respiratory nurses and community matrons described how they felt very vulnerable in their roles, as other health professionals did not understand them. They had to work hard to ensure that other clinicians accepted them and used their skills appropriately. Many perceived that they were 'dumped on' by medical and nursing colleagues off-loading unpopular tasks, or challenging patients with needs that are particularly difficult to manage with available resources. These findings on the problems experienced by specialist nurses reflect other research which has commented on the lack of support and mentoring available and the need to clarify the role of new posts and to ensure that all parties are aware of the boundaries and objectives of new posts (Goodwin et al, 2004; Jasper, 2005; Lloyd-Jones, 2005; Powell, 2006; Savage and Scott, 2004).

Boundaries between clinicians: contest at the interface between sectors.

The relationships between key medical staff from primary and secondary care, and the PCO, were instumental in shaping the outcome of inter-professional contest and negotiation on new roles and service developments.

Where relationships between secondary and primary care were working well, and the changes proposed by PCOs were not perceived as threatening to consultants and/or hospital services, it was easier to plan and implement service change. A service development team (as in Team PCO) which included key players from both primary and secondary care and the PCO was able to align different interests so new roles were accommodated, and even encouraged, as they were seen to contribute to a joint vision. Where strong relationships between primary and secondary care did not exist or had broken down, service development stalled, and a contest for 'territory' between the two sectors emerged.

In two of our case studies we observed services developing without contest between primary and secondary care. In Team PCO, there was an immediate benefit for the lone respiratory consultant in the local DGH to participate in the development of the GPwSI service, as he was able to reduce the backlog of referrals that had built up prior to his appointment and then begin to develop his department further by extending the services he provided. In Commissioning PCO, the community specialist respiratory service was closely linked to the hospital trust and had little primary care involvement, though this may change as PBC groups are established.

By contrast, in Merged PCO the situation of the hospital trusts was more complex and this created contest as they defended their interests. The hospital trusts interpreted the PCO's Turnaround-driven roll out of the GPwSI service across the whole county as an attack on their organisations

and resisted the development of the service, something which limited the scope of the GPwSI role. Consultants here were increasingly aware of the need to protect their interests in the face of increased competition:

> *"I think the current structure of the health service has introduced, I think unhealthy, competition, you know, in the past you wanted to I think be more positive about these initiatives whereas now, because with the one hand if PCOs do this they're taking away your own service you're much more concerned about it."* [Merged PCO: Respiratory consultant University Hospital]

Specialist nurses were not directly involved in these negotiations and contests, although they might have a view on them (as in the example of the comments made by a hospital specialist respiratory nurse on Payment by Results and PBC). Nurses' roles tended to be defined in relation to the roles of doctors, both by themselves (cf comments by the community matron) and by doctors (Larkin, 1983):

> *"...could we have replaced him [GPwSI] with a nurse? I think not. I think you do need a doctor lead in. I'm not saying that because I am a doctor; it's because working with a lot of nurse specialists (and we are very dependent on them in the meantime here due to lack of doctor support), is they can be very good at specific aspects but become very unsure of themselves when they're outside of their particular field and that's because they don't have the broader and deeper training that one gets through medical school...so I think at the end of the day there needs to be a doctor controlling the medical aspects."* [Team PCO: Respiratory consultant]

Boundaries between clinicians and managers: arguing 'the Business Case'

The environment of increased contestability and emphasis on value for money of services introduced the need to argue for services on the grounds of cost-effectiveness. 'The Business Case' became a key argument and tool in the definition of territory as the relationships between clinicians and service managers became increasingly important.

There has been much debate in the literature about the struggle for power and dominance between managers and doctors at different periods of NHS change and development (e.g. (Davies et al, 2003; Davies and Harrison, 2003; Degeling et al, 2006b; Plochg and Klazinga, 2005)). There is growing recognition of the nuances in the relationships between doctors and managers: "*while at a collective level it is useful to continue to think of doctors and managers as adversarial superpowers, the micro-level reality is more complex and reveals some fascinating compromises, alliances and innovations.*" (McKee et al, 1999).

These nuances were seen in the case studies. On the one hand, there was evidence of traditional tensions and conflict of interests to be managed:

> *"It might be perhaps information not being fed back directly to clinicians as much as I would like it to, whereas it's going to clinical service*

managers who are perhaps keeping a lot of it to themselves and saying well, we don't really need to know and everything's going all right. Now, probably a lot of doctors will accept that because I think the less we have to do management things, the better. Unfortunately you can't stay aloof from management and commissioning things because you're likely to end up with nothing one day because the people who are aggressive would have gone in and grabbed the money there is." [Team PCO: Respiratory consultant]

However, in Team, Merged and Commissioning PCOs there was evidence of successful clinician-manager relationships that enabled service development to take place. Collaboration between clinicians and managers was a key ingredient which enabled them to harness the strengths and expertise of each:

"He [a PCO manager] has been the person that the PCO has tasked with moving [things on]…And both he and I have worked quite closely together and he's the one who has done all the work in terms of taking proposals through the various [committees] of the PCO, putting together business cases and all those sort of things." [Merged PCO: GPwSI]

"…[PCO manager] has a superb sort of management look on things and you know, whereas clinicians tend to go off on tangents, she'll take us back and say 'Well, look, this is what we need…I think the success of the group is due to her sort of holding things together and getting us corralled into the right frame of mind and getting things up and running…[Clinicians] have this wish list but [PCO manager] brings us down to the reality of how things are and how we have to present things". [Team PCO: GPwSI]

The collaboration between clinicians and managers in establishing 'the business case' was an important part of strategies to claim territory and in constructing a field of expertise, which went beyond a clinical role (Fournier, 2000).

Personal relationships in boundary work: the 'clan' versus the 'contract'

A rationale of commissioning as a market-based mechanism of service development is to weaken the influence of professional and occupational 'clan' interests in service development (Broadbent and Laughlin, 2002). Our findings suggest that professional interests, through 'clan' type relationships are key enablers of development. Paradoxically, in the time of turbulence and upheaval during our study these relationships had a particular importance because new formal ways of 'getting things done' were not functioning. Although these relationships could be disruptive of developments, as in the contest between the consultants and the GPwSIs in Merged PCO, they could also introduce an element of stability into arrangements and contribute to sustainability. Relationships and networks between clinicians and managers were becoming a key resource in boundary work as new territory was established through arguments of cost-effectiveness of services.

Much of the respiratory service development observed in the case studies appeared to originate from, or be enabled by, personal relationships, whether as professional colleagues or as personal friends. A key factor in initiating and developing a new post or service was the presence of an individual who was well-known to local clinicians and was respected for their clinical experience and expertise. Personal relationships were also important in enabling individuals to 'work around' structural, cultural or contractual boundaries; and in 'buffering' services during times of organisational instability and change.

There was greater fluidity around professional boundaries (e.g. in determining who was 'allowed' to carry out certain activities) when individuals knew and respected each other, as seen in the collaboration between the GPwSIs and their mentoring consultants in Team PCO and Market Town Merged PCOs. Conversely, individuals who moved into an area to take up a post, for example the GPwSI in Coastal PCO in the new Merged PCO and the specialist respiratory nurse in Rural PCO, described how it took them a long time to feel accepted.

Relationships between individuals who worked in primary care and secondary care were important in enabling integrated service development that crossed traditional organisational boundaries or existed in the intermediate area between sectors. These relationships enabled individuals to 'work around' organisational boundaries, as seen in Commissioning PCO, where the respiratory consultant and the lead Community Respiratory Team nurse were able to arrange mentorship between individuals working for different trusts. The close personal relationship between the GPwSI and his mentoring consultant in Team PCO also facilitated changes in the primary care–hospital interface.

A service that was underpinned by a network of effective working relationships between several different stakeholders (e.g. between GPs and specialist respiratory nurses, GPwSI and consultant physician as well as between the hospital trust and the PCO) seemed better able to withstand temporary instability in one of the organisations (e.g. in the course of organisational re-structuring) than a service that was dependent on one or two key relationships (e.g. between a clinical service and an individual commissioner at the PCO).

Personal relationships in boundary work: GPwSIs and specialist nurses compared

Personal relationships and networks linking the individual to groups, events and processes where key decisions about service development and resource allocation were made, determined the extent to which clinicians in new roles were in a position to lead and shape developments. We observed striking differences between the GPwSIs and specialist nurses in our case study PCOs. In general, GPwSIs and consultants had and used local (and national) relationships more effectively than specialist nurses who seemed to lack access to influential, decision-making networks.

For example, by virtue of their profession, GPwSIs had access to PBC Groups:

"..and one of the principal ways a PBC consortium can make a difference is actually to develop GPwSI type services to reduce dependency on acute care. My service has been picked on by the local consortium as being, if you like, a sort of exemplar of what could happen in other specialties and we had a meeting with the whole PCO and the clinicians in the PCO some weeks ago which focused on respiratory pathways, really promoting my clinic to the whole PCO, which was very useful. So I think PBC is another, whether it's coming from the centre, I think it is the logical outcome of PBC that there will be GPwSI type services." [Merged PCO: GPwSI]

Nurses often lacked these connections:

"...but it's difficult to know really the management pathways [strategy] to actually take, you know. I mean, because [PCO manager] I don't think is directly PBC, there are other PBC [groups] around, and I wonder if I shouldn't be approaching them, it's difficult to know where to turn really, and in the meantime patients sort of, you know, sit there desperately in need of the service." [Merged PCO: Specialist respiratory nurse]

The GPwSIs and many of the specialist nurses in our study all had contacts with a historically GP-initiated national network of clinicians and researchers who promoted primary care interests and the GPwSI role nationally. This gave them access to information and contacts, which supported them in their roles:

"Yes there is a national group and in fact there's a national meeting in a week's time, an overnight, sort of Friday afternoon and Saturday morning meeting which I'm going to which looks good and that is good...And there's somebody coming from the IMPRESS team [a joint BTS and GPIAG working group looking at service reconfiguration and commissioning processes] , have you come across that? So there's somebody who's on that working group coming to sort of report back on because I mean I think that group is trying to have dialogue between secondary and primary care at a national level and that working is really important." [Merged PCO: GPwSI]

By contrast, nurses and community matrons, used these formal networks, which could link them to a national power-base, less effectively. Instead they relied on informal usually local groups.

"We are hoping to try and pull together all the community matrons in the pan-PCO area and we're hopefully having the meeting here just to sort of support each other really and find out what people are doing, what training issues they've come across, you know, what's their workload just to try and pull it together and be a bit more cohesive really, where do we fit in with COPD, you know, what do they do with their patients, their heart failure, diabetics, that kind of thing." [Merged PCO: Community matron]

The GPwSI as an 'elite' role

GPwSIs' networks put them in a position to lead and shape service developments. This political function may be as important as their clinical role in understanding and evaluating the role. More widely, the development of the GPwSI role can be seen as part of a trend towards internal divisions in professions between 'elite' groups maintaining control and autonomy in the new context on the one hand, and, on the other, 'rank and file' groups with reduced autonomy carrying out increasingly routine work (Freidson, 1988).

The position of influence enabled a GPwSI to define and pursue a vision of the GP role in the new organisational context of strong managerial control and increased contestability:

> "But basically they [a private provider] said 'Well, we'll give you so much for the practice and you'd be paid 70.000 a year salary for that'. That's the same as new people coming off the block, and I thought 'does experience not count for anything?' That made me realise that really experienced GPs are going to be crushed and we're going to lose a huge amount of expertise and I think it is a real threat to the profession – I really do. I think that as GPs we've been badly advised by the people who are meant to guard our interests. But I think realistically there is a …danger that you'll end up with a lot of salaried GPs – fine, that's OK – but where does the expert fit in? So that I think you've got to develop, I mean I think you've got to use that expertise because at the end of the day who's going to design services – are they going to be people who perhaps are administrators, you really want people who have seen patients and are basically involved, clinicians I think it has to be."
> [Team PCO: GPwSI]

6.11 Conclusions

Our case study findings reflect the conclusion of other studies that contest between clinicians about occupational territory was a key element of workforce development. Our findings also suggest how this boundary work is changing in the context of an increasingly market-based healthcare system. Relationships were realigned around the increasingly formalised commissioning system and requirements for the 'business case' and proof of cost-effectiveness.

Collaboration between clinicians and managers is key to constructing new territories of expertise through a language of cost-effectiveness and organisational efficiency (Sanders and Harrison, 2008). The new territories of expertise constructed by GPwSIs went beyond a clinical role to include strategic involvement in shaping services.

In the period of organisational change and upheaval during which the data collection for this study took place, some of the existing relationships which had sustained service arrangements were disrupted and realigned. The formalisation of commissioning, with a stricter division between

commissioner and providers based on contract, could further disrupt relationships.

Personal relationships and access to networks linked to decision-making power were an important part of new 'intermediate care' specialists' ability to shape developments and establish a territory. These networks, to be effective, needed to include both managers and clinicians. Personal relationships based on professional and collegial interests were an important resource in service development in the period of instability and change. Some professionals, especially GPwSIs, enjoyed wider links with professional groups who could provide advice, support and lobbying.

Policy on workforce development emphasises the 'breaking down' of professional boundaries to create flexible services addressing patients' and organisational needs. This policy may be based on an unrealistic premise. It is precisely through relationships and alliances, forged not only through professional group identities but also developed around a shared interests and vision, that services are developed and care provided. Understanding and harnessing this process is important to successful service innovation and workforce change.

7 GPwSI role, training and accreditation

This chapter draws together the findings from phase 1 and phase 2 of the study in relation to the role, training and accreditation of GPwSIs.

The definition of a GPwSI, as opposed to an 'interested GP' was unclear, at least in part because at the time the phase I interviews were conducted, there was no approved process for accreditation and interviewees interpreted the role differently. Six of the PCOs had GPwSIs or 'interested GPs' who were working at trust level rather than just being a nominated respiratory lead within their own practice. We subsequently recruited two of the PCOs with a GPwSI service (one established and the other in training) as case studies. In addition, two of the PCOs involved in the merger had a GPwSI or an interested GP providing advice to the PCO.

7.1 Summary

The role of the GPwSI

The GPwSIs in our screening interviews and case study PCOs were all involved in the strategic reconfiguration of local services, most had a clinical role often as leaders of a clinical team and most had an educational remit, where their status as acceptable sources of advice and education to GPs was valued.

Training and accreditation

GPwSIs were being accredited through different routes: some were undertaking formal training courses and some were being accredited by portfolio on the basis of their experience. Training and accreditation were seen as important, both to satisfy governance requirements and also to provide specialist credibility for the GPwSI.

Mentoring with a secondary care consultant was valued not only to complement formal study but also to build relationships between primary and secondary care.

Both GPwSIs and specialist nurses identified that there was a range of generic skills (e.g. team-building, financial planning, negotiating, service development) that they needed to acquire to be effective in their new roles and that such generic training was not readily available.

7.2 The role of GPwSIs

Existing and potential roles for GPwSIs varied between PCOs, but always extended beyond providing a clinical service:

> "I think those do encompass the main priorities and they're certainly what I seem to spend most of my time around really and so there's been quite a lot of involvement with the PCO from a strategic point of view, certainly the patient care point, the patient care is happening and education hasn't been perhaps quite so prominent this year but certainly in previous years education has been a big part and I certainly go out to practices quite regularly and talk to them about COPD and asthma, so yes I would see that as part of my role. I mean I guess the other thing you could add into that although it isn't, would be research though that

isn't something that we've formally got involved in at the moment."
[Merged PCO: GPwSI]

7.2.1 Clinical role

All of the six GPwSIs or 'interested GPs' described in the screening interviews were, or planned to be, involved with a clinical service, usually as part of an innovative community-based service designed to reduce out-patient referrals or admissions. However, at the time of the interviews only two were commissioned personally to provide respiratory care. Two led multidisciplinary clinical teams, though personally had limited clinical roles, whilst one ran a referral management service. Two were undertaking respiratory clinics within secondary care, one as part of his training, the other because the PCO had been unable to fund her intended role as a GPwSI:

"Though we haven't really put it in place, we have started to talk about part of this GPwSI activity being peripatetic and going out to a GP surgery where a group of people have been identified, a group of patients who have a common problem, say COPD and we've talked about doing what we've loosely referred to as a big clinic where there might be the GP, a nurse, a physiotherapist, a stop smoking advisor, those people would all be available for, let's say, a group of 10 patients." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"We do a referral management centre and I do that with the respiratory nurse consultant. All referrals for respiratory medicine come to us and we decide where is the most appropriate pathway to go." [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"I mean, obviously we're talking about hospital admission avoidance…And we're looking at the whole sort of, day hospital type of role within that. And looking to introduce a GPwSI there as well, you know, that kind of model where they can have quite a quick multi disciplinary geriatric assessment." [PCO 28, respiratory nurse service, Interviewee: Nursing manager]

Important attributes of a GPwSI clinical service included convenience for patients, accessibility to community staff, and an initial point of referral which could help colleagues considering referring to a specialist clinic. Opinions were divided on whether it was a cost-effective option:

"What I really like about it is the fact that it's so accessible and that you don't have all this personal secretary business and trying to get through to a consultant, you know, you don't have those barriers, whereas with this one it's much more accessible and even if you just wanted to go and ask for some, you know, some information about something…you feel that you can." [Merged PCO: Community matron]

"So we're thinking about how we could improve the way we look at suspected obstructive sleep apnoea because I think the GPs have concerns or it's not clear to them whether they refer, which snorers they

refer to ENT and which ones they refer to us". [Commissioning PCO: Respiratory consultant]

"There's the fact that GPs with a special interest, provided they're adequately trained, are really grounded in primary care, they have a wide experience base and if they are properly trained I think they can provide a superb service." [Rural PCO: GP]

Other interviewees expressed doubt that a GPwSI could fulfil a specialist role and believed that at best the GPwSI would always need the support of a secondary care clinic:

"You see having worked with, you know, GPs and things they again they'll only become specialist to a certain level, they can't become secondary care specialists, do you know what I mean?" [Commissioning PCO: Community specialist respiratory nurse]

"But usually GPs with a special interest they would do a clinic in secondary care…I would imagine a GP with a special interest, they can't do it with lung cancer because they need the bronchoscopy and the CT, they can't deal with lung disease because they'd have to organise lung function tests, biopsies, so…I wouldn't call that special interest particularly, I would call that a slightly enhanced service." [Rural PCO: Respiratory consultant]

7.2.2 Strategic role

All the GPwSIs or 'interested GPs' were involved at PCO level, offering specialist advice and involved in strategic planning, being described, often in glowing terms, as local 'champions' for respiratory care. The GPwSIs in the case studies all had important strategic roles within their PCOs including leading the local respiratory team in Team PCO, and chairing the implementation group rolling out the GPwSI service in the Merged PCO:

"Given the GP we've got, if [GPwSI] wasn't here in the city it probably wouldn't have happened but he is very highly esteemed, very knowledgeable, has had papers published and things, he knows his stuff and so therefore to, yeah, I think his presence here was critical to that and his enthusiasm." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"I [GPwSI] lead on the COPD strategy for the 3 PCOs, so I chair that group. But I have been working with the key long term conditions senior manager across the PCOs and we have been designing a service specification. So we are trying to get that service specification across the care pathway as kind of the model for which Practice-Based Commissioning clusters will commission services." [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"The PCO are using me at the moment but we are discussing about formulary guidelines and everything else and in that respect they value my knowledge and my judgement and my experience." [PCO 16: respiratory nurse service, Interviewee: interested GP]

"I'm working with the PCO in developing this plan for respiratory care so it's more about service development that I'm doing rather than seeing patients at this point of time". [Team PCO: GPwSI]

7.2.3 Educational role

The standing and influence of the GPwSIs and 'interested GPs' amongst their colleagues was cited as important in enabling them to raise standards in primary care either by providing formal training, by spreading good practice through a 'hub and spoke' model or from an academic perspective

"I provide education, mentoring and support to primary care clinicians" [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"We developed sort of a vision…that envisaged basically utilising the services of a GPwSI with a community respiratory specialist nurse as a support and also filtering down to all the other support staff as needed …to improve the care that's given in primary care through education." [PCO 14: GPwSI service, Interviewee: GPwSI]

"My particular interest is in the education and training structure and I'm no fan of surgical treatment centres that ignore education and training and cream off, you know, the clinical load only, don't provide either a strategic or a training service. I think training is an absolute part, integral part of all NHS activities…I think they (GPwSI services) have a very powerful training role, perhaps not yet been fully developed although I have to say both dermatology and respiratory offer a service that if we ask them to have trainees and to teach they do so willingly and very helpfully." [Merged PCO: GP]

"There is a really good piece of audit that's being undertaken across practices where we've got a GP locally with a special interest who's developed through an educational route, a good audit tool to review the work that's going on in practices to bring things up to scratch". [PCO 30, GPwSI, Commissioner]

The GPwSIs in the case studies acted as mentors to the specialist respiratory nurse teams, or informally provided training:

"However we have just started up a mentorship session for me each month that I go to him for mentorship, it's like informal clinical supervision really with him." [Team PCO: Community specialist respiratory nurse]

Interviewer: *"So it doesn't cause any feelings of being threatened within the roles?"*

GPwSI: *"No, it's great, completely the opposite, if the nurse has got time she'll often come in and sit in with me while I'm taking a history because I think that's quite a useful learning experience for her, and I certainly don't feel at all threatened by the nurses, I mean I try and encourage them to come and sit in with me because I'm trying to encourage them to actually take over the follow-ups on their own."* [Coastal PCO: GPwSI]

Although specialist nurses also provided training for primary care, particularly practice nurses and community staff, several expressed reservations about teaching GPs, despite considerable experience as respiratory trainers. This could be attributed to lack of acceptance of their expertise by medical colleagues or to a different approach to learning:

"Yeah, GPs think they know it all, they're a pain to teach." [Merged PCO: Community specialist respiratory nurse]

"I wouldn't be able to use the same approach with a GP because what they want is statistics and I don't think I'm the best person for that because I hate them, you know, you stick a graph up in front of me and I'm thinking yeah so what, so what if 1 out of 5 people develop, what I want to know is what's that got to do with the patient…how does it relate back to my practice." [Rural PCO: Community specialist respiratory nurse]

7.3 GPwSI training

It was widely acknowledged by both GPwSIs and specialist respiratory nurses that a high standard of clinical expertise was fundamental.

"So I think if you're looking at the GPwSI role, well you've got to obviously ensure that it's properly, the education element is there and you've reached a high standard. I think it depends then on what sort of a role you want. I have, to date, resisted setting up an intermediate service for a number of reasons. Because I think, first of all, I feel that I need to have necessary qualifications to be able to say to my GP peers 'well look, I'm in a position to see other patients or whatever for you'." [Team PCO: GPwSI]

"…. but certainly four of us this year have, we've been away and done M&K Chest and Heart examinations, [Short courses for nurses and allied health professionals (M&K Update Ltd,2008)]. *We do quite a lot because we feel, you know, I think if you are specialists and you're saying to other people you should be doing this then you have to know that it's the right thing."* [Merged PCO: Specialist respiratory nurse]

It was recognised that this expertise could be acquired from experience (for example, many years as a Hospital Practitioner) or by undertaking a formal diploma course or higher degree (Bradford and Airedale Teaching PCT, 2008; Education for Health, 2008).   The GPwSIs in our study had experience of both these models.

Formal qualification

A formal training course was seen as providing confidence in clinical knowledge and skills for GPs with little specialist respiratory experience, or who felt that they needed the credibility a formal qualification could offer.

"Well its hard work. I've done one module which is the COPD module. I'm now on the second one which is the asthma one. I'm, you know, spending quite a bit of time doing it as best I can, studying and doing it.

I mean I've found it a very helpful exercise in terms of improving my skills and giving me a degree of confidence to be able to manage more difficult cases that I would otherwise not be able to manage in primary care. [Team PCO: GPwSI]

Formal training courses were new, and the programmes were still being developed in discussion with potential specialist practitioners (Bradford and Airedale Teaching PCT, 2008). Key features were that the course should be practical, grounded in the practitioners' usual work, and focused on the needs of specialist practitioners working at intermediate level. Dedicated time for training for the duration of a course (e.g. two sessions a week over 18 months) was not always easy to fund. This compares with the 6 month distance-learning asthma or COPD diplomas regarded as core training by most of the specialist respiratory nurses.

"Bradford have got a record of doing diplomas for GPwSIs, and its not just the academic aspect of it, it means to be part of it you've got to be affiliated with a PCO and have a role within the PCO." [Team PCO: GPwSI]

"You know, 2 sessions a week really isn't enough but it's all we can get and I think [GPwSI] accepts that, you know, it's better than he thought a couple of weeks ago [Team PCO: PCO manager]

"Yes, the asthma one [Diploma course] I did in 1991 so it's quite a long while ago but the COPD one was in 2000 and it was a six month distance learning pack and there was two days that you did some training and then you went back for the exam after six months." [Merged PCO: Specialist respiratory nurse]

The 'parachute PMS scheme' which aimed to attract GPs to their under-doctored area by offering a programme of specialist training combined a one year part-time GP post with formal training at a local University and mentorship with a respiratory consultant. Although disbanded for financial reasons, there was some evidence of success with this approach as *"roughly half of the GPs .. were still with us and still in that area of special interest"*. [Merged PCO: PCO manager]

"I was employed by the PCO for one year under their [GPwSI initiative] and the purpose of that job was for me to be trained in my specialist interest … and the idea of this programme was that at the end I was going to be a GP with a respiratory interest. [Merged PCO: Small town GPwSI]

"So if you broke that down into days you can imagine that typically this varied from GP to GP because we agreed the training package that suited their needs, but typically you might find that a GP would spend three days working in a host practice, one day at the [University] and one day at the hospital working alongside a hospital consultant actually practising hands on skills. [Merged PCO: PCO manager]

Portfolio of experience

Four of the GPwSIs whom we interviewed had achieved accreditation by submitting a portfolio of experience, reflecting the early stage in the evolution of the GPwSI role and the development of training programmes. Most of these practitioners had a prior interest in respiratory disease, and most were acting as 'champions' for respiratory medicine. Some were contributing at national level to the debate about provision of care; others had a background in research. Ironically, although they were aware of the need for training for their specialist role, when courses were being devised they were potentially seen as the 'experts' who were invited to teach.

"The situation for me is that my ability to be a GPwSI is based on the fact that I've been working in a hospital respiratory medicine clinic for the past 9 years doing a weekly session, seeing outpatients, so I've obviously had a fairly, fairly extensive experience of seeing respiratory outpatients in that setting...so I'm a GPSI accredited by experience really rather than a formal qualification." [Merged PCO: Respiratory GPwSI]

"And basically we took the template of what the GPIAG had done, and we basically piloted it with myself. So I put together a portfolio of my experience and fulfil the various aspects of that. And then I went through an accreditation panel with a local respiratory physician, a manager, a PEC manager. ... and also with a respiratory physician. So I went through that process to get that accreditation" [PCO 17: GPwSI-led service, Interviewee: GPwSI]

"Wel,l I just had a joke with him and said 'Oh good', I said 'there will be a course I'll be able to go on', and he laughed and he said 'Well actually, we were expecting you to lecture on it'..... I recognise that as a big problem because, you know, it's too easy for people to look at me and say 'Well why do you think you know what you're doing?' I've done a lot of research into the management of COPD in primary care, I've set up COPD services in three practices .... and I guess most of its just clinical experience really and a lot of enthusiasm. [Merged PCO: Coastal Respiratory GPwSI]

By contrast, a portfolio option was not formally described for accrediting specialist respiratory nurses who thus felt they needed to complete the formal training even if they had considerable practical experience of respiratory disease.

"I haven't done my diploma in COPD .... but I'm planning to do that and I have sponsorship for that, and its really just to get a piece of paper at the end with my name on but its, as far as I'm concerned I feel I know most of the things." [Merged PCO: Specialist respiratory nurse]

Mentorship

Mentorship with a respiratory consultant not only *"fulfilled the need for practical experience"* but could also facilitate relationships between primary and secondary care as it allowed mutual understanding of the roles and

issues.   One of the mentors, however, highlighted the lack of precedent and definition of the standards required for training a GPwSI, reflecting the evolving nature of the role and accreditation process.

> *"We needed the support of the local hospital because we recognised that even mature GPs with a special interest can't operate without a good relationship with a hospital consultant, and if they're training to become a GP with a special interest they need support from that consultant, they need mentorship and they probably need some practical hands on training."* [Merged PCO: PCO manager]

> *"[GPwSI] and I had to do some homework because I wasn't quite sure what was reasonable to try and teach him as a GP because I was used to teaching chest physicians but not someone who's going to do it as part of a different job as well and at a different level."* [Team PCO: Respiratory consultant]

> *"And the other argument is that we're sitting next to each other in a clinic where we can compare notes, you know, I can say to him well, you know, what's happening your side of the fence?"* (Team PCO: Respiratory consultant)

Mentorship could be time-consuming but, in addition to the personal benefits to both the GPwSI and the consultant, there were long-term advantages as GPwSIs were seen as likely to contribute to the local respiratory service for many years.

> *"The other good thing about this of course is the [hospital] doctors in training are there for short spells and just when you've taught them the job they move on to something else so you have no continuity, so people with intermediate skills are usually more loyal in the long run to service and help with the continuity and also training of new people as they come through."* [Team PCO: Respiratory consultant]

GPwSIs in their turn acted as mentors to their specialist respiratory nurse colleagues, potentially helping to prevent the sense of 'isolation' that could result when nurses moved from the supportive structure of hospital practice into the community.

> *"I feel that I really miss out myself on mentorship, supervision, you know, reflection all that sort of stuff, its very hard. I feel, I mean obviously I'm in an acute trust and I feel specialist nurses as a body in my acute trust don't fit anywhere very well, we sit in our own directorates, we don't sit with a corporate body and people actually don't have a clue what you do."* [Merged PCO: Specialist respiratory nurse]

> *"It's very difficult. Where I was before I knew all the consultants, I'd worked in outpatients, I'd worked in the chest clinic …. It was, you know, fantastic, I mean I knew exactly where to go and whom to talk to and I assumed in my naivety that that's what it would be like when I came here when it's not really like that at all and to be honest nobody tells you who you're meant to – there's a lack of communication."* [Rural PCO: Specialist respiratory nurse]

"We tend to talk a lot on the phone but we don't actually do clinical sessions together. However we have just started up a mentorship session for me each month that I go to him for mentorship, its like informal clinical supervision really with him." [Team PCO: Specialist respiratory nurse]

Other essential skills

In addition to developing clinical expertise, the GPwSIs all highlighted the importance of acquiring new skills in order to fulfil the strategic, management and educational functions that their GPwSI roles entailed:

"We're clinicians first and foremost that's why we're in the job and I think, when you're dealing with service development it's about management, it's about team development, it's about leadership, it's about negotiating skills, it's about the politics of the situation. It's a much wider picture and to a certain extent these are not always inherently – a lot of clinicians don't have those skills, they've never had to deal with them before. So I think that's what makes it difficult." [Team PCO: Respiratory GPwSI]

"You're actually implementing it as you go along and trying to work out the best thing to do at each step and having never had any formal management training it's quite challenging and doing it outside the sphere of, the comfort zone of my practice as well." [Merged PCO: GPwSI]

Continuing professional development

Continuing professional development was also a challenge as *"there aren't any courses aimed at the clinical needs of respiratory GPwSIs"*, and conferences aimed at secondary care specialists were not entirely relevant. National professional organisations (such as the GPIAG) and networks were seen as important in providing mentorship and supporting GPwSIs in developing their roles.   Nurses often described local networks as important sources of support.

"I try and go to at least one conference a year which is aimed at hospital doctors but for the care of COPD…it's quite interesting listening to hospital doctors and you realise how far, how different we are, apart, but I didn't learn a huge amount that would have made a huge difference to what I do on a daily basis." [Coastal PCO: GPwSI]

"It'll be incredibly important to have (a) network of peer support because there isn't anybody directly comparable locally not even in another specialty" [Merged PCO: GPwSI]

"The other thing which can often be difficult for [Rural PCO] is when you set up particularly specialist roles whether it's nursing or other PCOs roles is having the access to the specialist network that they need to keep their competency and their advanced level of practice, you know, to be connected." [Rural PCO: PCO manager]

Resources to enable continuing professional development could be a challenge as nurses described the difficulties of arranging time out from their clinical duties and having to look for sponsorship to support their attendance at study days.

I'm sure this is not singular to this Trust but to secure time and funding for any training is a major issue and virtually impossible, we have had no funding at all from within the Trust for training so we have to beg and borrow for money to go to training." [Merged PCO: Specialist respiratory nurse]

"But we hear about the courses and it's too late, you know, our clinics are booked up and it would mean me having to, you know, cancel 20 patients and apart from that there's nobody else to do it." [Rural PCO: Specialist respiratory nurse]

The nursing team in Commissioning PCO described the paradox of a well structured approach to team development, which proved *"impractical"* to deliver because of the demands of delivering against performance indicators. Addressing this balance was described as a responsibility of commissioners.

"We're very well supported in the fact that we have, we draw up a team development plan for the whole team, so ours is just in the throes of being pulled together now and in that everybody has an opportunity as an individual to say what their learning needs are or what their training needs are and then that maps out against what the service needs and then we get some sort of prioritisation." [Commissioning PCO: Specialist respiratory nurse]

"It's all very idealistic saying 'Yes. Let's do training', and that's really important for quality. But you do have to match that against performance because if you do not perform we will get money withdrawn and then we can't support the service, we can't then do education so it's actually very challenging" [Commissioning PCO: Specialist respiratory nurse]

"Well that's something we really need to understand how that will work in the future because if we're looking at sort of provider services and we put out a spec [specification] for something we obviously hope that the education is involved with that, but I think we need to look at what education are out there and what needs are out there in respect of specialist services and whose going to commission that and pay for that really." [Merged PCO: PCO manager]

7.4 Accreditation

At the time of our phase 1 interviews, the suggested process of accreditation was interpreted differently by individual PCOs, resulting in an undefined and evolving process:

"I mean obviously once you have the expertise and have a certain amount of credentials there you're then in a position to be able to

negotiate slightly better from that point of view, but it's sort of a give and take scenario at this point in time." [PCO 14: GPwSI service, Interviewee: GPwSI]

"Basically we took the template of what the GPIAG had done and we basically piloted it with myself so I put together a portfolio of my experience and [how I] fulfil the various aspects of that. And then I went through an accreditation panel with a local respiratory physician, a manager, a PEC manager." [PCO 17: GPwSI-led service, Interviewee: GPwSI]

The publication of central guidance in April 2007, (Department of Health, 2007) occurred during the year of our case studies and was generally welcomed as it formalised the accreditation process, though it meant that existing GPwSIs had to *"reapply"* and there was some concern that the more complex requirements might be *"quite off putting for people"*. There was some concern that the accreditation process involved the support of a consultant who, in some cases, might be antagonistic to the development of the GPwSI role. GPwSIs with considerable experience in respiratory care (e.g. as a hospital practitioner) sought accreditation by portfolio (Gruffydd-Jones, 2005); others chose to undertake formal training (Bradford and Airedale Teaching PCT, 2008; Education for Health, 2008):

"Well I mean something that I'm very concerned that we do right in the GPwSI clinics is that we get our clinical governance and our clinical audit good so that we can actually provide good evidence that what we're doing is effective and safe, etc. We're all in the process of going through being re-accredited and the PCO are implementing the government's guidelines on accreditation on GPwSI, so I sent in my papers on that last week and that did involve getting [local consultant] to sign me off as being competent which he did do. I mean he didn't write anymore than he had to in the reference but he did sign it." [Merged PCO: GPwSI]

"We'll need to give, make sure that the GPwSIs are accredited, so we'll need an accreditation panel, we haven't, we think we know who'd be on that and, but we haven't bottomed out, you know, what exactly they will look at but we'll go by the NICE, the Department of Health guidelines on GPwSIs and so on for that, but there's bits and pieces still to be done." [Merged PCO: Commissioner]

Key advantages of the formal accreditation process were to define the specialist role and establish credibility amongst colleagues (including sceptical secondary care specialists) and to ensure patient safety by satisfying governance requirements. It was also seen as offering an attractive career pathway for GPs, and two PCOs used the provision of GPwSI training as a means of recruiting of young doctors to their under-doctored area:

"The other side of the argument is firstly that you hear too many so called specialist primary care providers who actually don't fulfil clinical governance in terms of their training, the numbers of procedures that

they're doing, the service that they're providing, we don't look critically enough at the standards that we need to adhere to." [Rural PCO: GP]

"*We'll be asking the provider, the contractual provider to ensure that anybody who's working as a GPwSI or as a nurse specialist with a GPwSI has appropriate accreditation, clinical supervision and monitoring, I think we've got to make sure we've done that otherwise I think our secondary care colleagues could, you know, if something happened, you know, they could shoot us down in flames.*" [Merged PCO: Commissioner]

"*We've also got a PCO sort of saying, you know, 'You deliver a service for respiratory. What evidence is there that it's a safe service with risk management? What experience has this GP got to deliver this sort of service?' and it's a real tension in terms of how do we provide public assurance that a GP with an interest in whatever has actually got the skills and competence to do that.*" [Team PCO: PCO manager]

"*The area is under doctored and yes, we are having difficulty in recruiting doctors…but we have got a big project…which we've had for about a year, which is focusing on recruitment of doctors. And it's a kind of, it's a multi-stranded approach, so you know, we are looking at career progression and things that we can do to keep doctors as well as attract new ones. And obviously appointing GPwSIs is part of our strategy.*" [PCO 6: respiratory nurse service, Interviewee: Commissioner]

7.5 Conclusions

The GPwSIs in our screening interviews and case study PCOs undertook clinical, strategic and educational roles within their PCOs. They were all involved in the strategic reconfiguration of local services, some leading service development and sometimes acting as champions. Most had a clinical role, though often leading a clinical team and not necessarily personally providing a clinical service. Most had an educational remit, providing informal teaching for members of the respiratory team, and also raising standards amongst their colleagues, where their status as acceptable sources of advice and education to GPs was valued.

Training, both experience-based and specific study, followed by formal accreditation were seen as important, both to satisfy governance requirements and also to develop the career and provide specialist credibility for the GPwSI. Mentoring with a secondary care consultant was valued not only to complement formal study but also to build relationships between primary and secondary care.

GPwSIs (and other clinicians operating in similar roles) have important training needs beyond those of their clinical speciality if they are to undertake the strategic roles within service development.

8   Phase III.   Patient perspective

The data presented here explore patient experiences when respiratory services around them are reconfigured. In the light of current rhetoric surrounding 'patient centred care' and the drive towards self-management, we aimed to acquire an in-depth understanding of how patients manage their condition within the context of changing respiratory services and how aware they are of the changes around them. In this section the terms 'patient', 'participant' 'respondent' and 'interviewee' are used interchangeably to describe the people that took part in the third phase of our study.

8.1 Summary

Awareness

Patients were aware of changes that affected their experience of immediate care provision including changes in the availability and type of providers, the resulting impact on their relationships with staff and the increasing shift towards managing care independently.

They also showed awareness of what was happening at regional and national level and great interest in the causes behind the developments, though none were actively involved in service redesign. Many contextualised their personal experiences of changes in their care in the light of national developments which they followed via various sources of information.

Involvement in self-care

While several patients were content with the trend towards self-care, at times others lacked contact and communication with their providers and felt abandoned, thus emphasising the need for flexible support at the boundary between professional and self-care.

Personal involvement in care not only took place at the level of self-management, but also in the securing of relationships and good communication with professionals, and the negotiation of care and treatment.

Our data illustrate not only the complexity of self-care, but also the fluidity of patients' care needs throughout the illness experience, the thin line between feeling empowered and feeling abandoned and the processes defining relationships between patient and provider.

8.2 Recruitment of patients

Of the 49 patients who contacted us, 31 agreed to participate, two were not eligible (one lived beyond the boundary of our case study sites, the other had contacted us after the data collection had already occurred), 15 decided against taking part after we had sent them the further study information and one died before being able to take part in a focus group discussion. The men and women we interviewed during the latter part of the case studies in 2007 had a wide range of conditions of differing severity and demonstrated varying ways of dealing with their condition. Tables 14 and 15 provide details on the numbers of participants per site and age and disease ranges.

Table 14.   Number of participants by PCO and contribution

	Phone Interview only	Illness Diary + Phone Interviews	Focus Group Discussion
Team PCO	2	4	1†
Merged PCO	-	7	4*
Commissioning PCO	1	4	10
Rural PCO	-	2	-

*3 of these participants also took part in the illness diary

† 3 participants had been expected, only one turned up. This participant was also involved in the illness diary.

Table 15.   Participant details by age category, gender and type of condition

Age range	Women	Men	Type of condition	Total number
40 - 49	2	-	Asthma (2)	**2**
50 - 59	4	2	Asthma (2), asthma and COPD (3), sleep apnoea (1)	**6**
60 - 69	1	10	COPD (5), asthma and COPD (2), bronchiectasis (2), sarcoidosis (1), lung cancer (1),	**11**
70 - 79	4	7	Asthma and COPD (1), COPD (9) sleep apnoea (1)	**11**
80 - 89	-	1	Asthma (1)	**1**
Total	**11**	**20**	**Asthma (5), asthma & COPD (6), COPD (14) sleep apnoea (2), bronchiectasis (2), sarcoidosis (1), lung cancer (1)**	**31**

8.3 Patient awareness

In the following section we explore patients' experiences of the services in the light of the changes taking place in respiratory care. We initially examine patients' awareness of changes in the health services around them. We then examine their insights on co-ordination of care, their experiences and thoughts on new professional roles, on the shift into the community, on the increasing emphasis on self-care and on access to new services. Finally, we look at how patients make sense of the changes around them and the resources they use to find out about local developments.

8.3.1 Awareness of changes in the health service

Increasing lack of co-ordination

Some frustration emerged in the interviews with what the participants felt was an increasing lack of co-ordination amongst their health providers. Statements that patients made regarding cumbersome and delayed referrals, having to repeat their basic symptoms to providers despite having been to the same practice for years, unexpected and unexplained discharges from hospitals and conflicting diagnoses suggest several barriers to communication between health professionals, leaving some patients worried, angry and confused about what was actually going on:

> *"I learned yesterday that I have been discharged from the chest clinic I have been attending for over 20 years. At present, I do not know why."* [Extract from illness diary: 50 – 59 year old man with asthma and COPD, Rural PCO]

> *"And then the hospital it's just very variable and as I say, last year I would have said I was seeing somebody every couple of months, but this year I've seen the doctor once and I haven't got an appointment with him for the rest of the year. So there's no consistency really. I don't really know what's happening."* [40 – 49 year old woman with asthma, Team PCO]

> *"So I said to him (doctor in the respiratory department) that unfortunately I had a hiccup in February, he said: "What's that? I said: "My chest infection". And he looked on the computer and brought my file up and the x-rays. He said: "Chest infection?", he said "My man, you had double pneumonia". (…) You see, my doctor missed that, the hospital missed it."* [60 – 69 year old man with lung cancer, Merged PCO]

Patients increasingly felt that their care was in the hands of many providers who they thought might, or might not, have full access to their notes, and who were unable to build a relationship with them due to the constant turnaround of staff:

> *"One goes and there's a new one and there is that feeling of incompetence. You go in and they have never seen you before and you have never seen him and he doesn't know what is wrong with you."* [60-69 year old man with asthma and COPD, Commissioning PCO]

> *"You're sort of whooshed through the system, although the system isn't that quick, but you get whisked through it and you don't really know them and you certainly don't know that they've consulted with all the other consultants at the other three hospitals."* [50 – 59 year old man with asthma and COPD, Team PCO]

Changing professional roles

Accordingly, many patients we interviewed were acutely aware of how changes in professional roles impacted on their personal relationships with providers. Patients commented on how they perceived the GP role had

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changed, and lamented the loss of the family doctor, a person they equated with a 'whole person' care provider who was known to the entire family and embraced a co-ordinator role, easing the navigation between primary and secondary care:

"Well, when I think back, if I go right back to the start when I was a child of course, your GP did the call-out and that was all very reassuring. And my poor old GP, when I was a kid must have been round I mean sort of once a week at night, I think just about, I seem to remember it like that anyway. Of course nowadays, I mean, I certainly, the last option ever is to call the night service out as you might say because you don't know who you're going to get and yes...so, I'm afraid I don't feel the same about it, you know, I don't feel as confident if I had an attack. I'd feel less confident than I did perhaps, you know, 40 years ago." [50 – 59 year old man with asthma and COPD, Team PCO]

"In the olden days, when you know you saw your GP and I think that was the role that tied things together. Now, but now, there are so many specialist clinics and, you know, you go to the asthma clinic at the surgery, you go to the diabetic clinic at the surgery, you see? You know, they're all compartmentalised I think." [40 – 49 year old woman with asthma, Team PCO]

With the perceived decline in 'family doctors', many interviewees welcomed the emergence of new professional roles and teams, some of whom they saw taking over a similar role to that of the GP *"in the olden days"*. Those benefiting from their services appreciated the community matron and specialist respiratory nurse for their ability to build relationships with patients and carers, their involvement, accessibility and availability in the community. Patients with access to respiratory teams also valued the continuity of care and support they offered. Several interviews demonstrated the positive effect of those health providers who considered patient care within the context of the patient's life as a whole and who were able to visit patients in their own surroundings, getting to know their environment, everyday routine, carers, children and general situation not only as a patient but as a member of society. The desire to be seen as a whole person, *"not just a pair of lungs"* emerged as an important theme throughout the interviews:

"The one on the community [respiratory nurse] seems to be more...I guess because it's a community role...she's more willing and able to think flexibly and in a kind of...a bit more laterally and think 'What can we really do to help? What kind of strategies could we do that can help you stay at home or that can help and make sure that you're all right, that you're safe and that you've got what you need?'" [40 – 49 year old woman with asthma, Team PCO]

"And she's [respiratory nurse] got not only my health, you know, as paramount too but my wife also. You know, she's making an appointment for my wife to go to the doctor, a different doctor to see about this depression thing. And she's also now got me somebody sitting with me for a couple of hours twice a week so my wife can go out

on her own because she's never been out without, with me when I've been out, you know." [60 – 69 year old man with COPD, Team PCO]

"Was visited by community matron. She calls weekly by appointment and to date has saved me from staying in hospital on at least three occasions. (…) She is more of a friend to my wife and myself, she is ultra-efficient in her medical treatment and is prepared to discuss plans, treatment etc. at any time. We look forward to her visits. Consider concept of community matron is excellent. It certainly works for me." [Extract from illness diary: 70 – 79 year old man with COPD, Merged PCO]

The GPwSI was only occasionally mentioned as few patients interviewed had actually met a respiratory GPwSI, either as they had never been referred to one of them or because they did not know they existed:

"I've never heard of him (the GPwSI) but then you tend to know the GP in your own practice and you don't really get to know about other GPs and if you need a referral you get referred to the hospital of course." [70 – 79 year old man with COPD, Merged PCO]

Some patients showed some understanding of why a GP would want to specialise and saw some potential advantages of generalists gaining specialist knowledge rather than the current system which called for referral to a consultant when faced with more complex disease-specific symptoms:

"The GP can't be a specialist in everything can he? He can have a reasonable knowledge of chest problems and heart problems and everything else but then that's his job done. He goes up to the specialist level, doesn't he, in order that you get diagnosed properly." [Focus group participant, Merged PCO]

Those patients who did have experience of the services from a GPwSI seemed to appreciate their care but sometimes were not entirely sure of their knowledge vis-à-vis the consultant:

"So he's the interested GP who specialises in respiratory troubles. But he's just a GP…not a consultant or anything." [70 – 79 year old woman with COPD, Merged PCO]

"Whether this is one of the sort of, I don't know, upgrades for doctors or whatever, but he's been working over there, but my view on the basis originally if I went back say 18 months I would say that his knowledge of somebody that suffers from COPD etc was virtually nil. Now in actual fact he is actually prescribing for patients with the illness." [60 – 69 year old man with COPD, Team PCO]

Shift to community care

Generally participants seemed very aware of a growing shift towards community care, and many welcomed the possibility of being cared for at home not only for the holistic aspect of the provision of care, but also because these new roles could prevent them from going into hospital. A number of patients expressed concern about some aspects of care at

secondary level, due to fear of Methicillin Resistant Staphylococcus Aureus (MRSA), the impersonal and busy atmosphere in hospitals and related experiences of neglect:

> *"Respiratory nurses. So they're there, to save you going to the doctors...they'll come. That's the sort of...they're supposed to stop you going into hospital, because you know, this MRSA, you know, when you're in there, you could get that so I suppose that's one they save."* [70 – 79 year old man with COPD, Commissioning PCO]

> *"I had a chest infection that was so bad I had to go into hospital about it. Everybody is so busy and they don't have time to tell you at whatever level is the one at which you understand what they're talking about. So they, you know, oh yeah you've got a bad chest infection we're treating it with some antibiotics, blah, blah, blah, blah, blah, good bye, good morning and they're off"* [70 – 79 year old man with COPD, Merged PCO]

> *"...when you hear, you know, ministers of the government saying that they've got the cleanliness of hospitals under control, they've got the diseases, the MRSA and the C dif under control it's a lie, a total lie. And I tell you something, I am petrified of going back into hospital."* [60 – 69 year old man with lung cancer, Merged PCO]

Others mentioned practical reasons for preferring care at home and provided descriptions of the difficulties in travelling to hospitals, the long waiting times and accessibility issues, especially in the rural areas:

> *"It's a bit of a job getting myself along in the wheelchair. Getting someone to drive us to the hospital. Then get the oxygen organised. It's a bit of a job but our community matron she checks me out every week. She checks me to make sure everything's alright. She's had a word with the consultant, well we all had a word together and he, she said: 'Would it be a good idea as I check him weekly for chest infections and other bits and pieces. Instead of us coming up here every six weeks and sitting and waiting whilst your staff do their job, can we not get the system going where if I think that if he needs a visit to see you I can arrange the appointment', which he agreed entirely. And it saves me. I'm being selfish, it saves me and it saves my wife."* [70 – 79 year old man with COPD, Merged PCO]

Similarly, several patients seemed aware of the geographical catchment areas within which some of the new professionals worked, and regretted that they lived outside these areas and therefore had to go to hospital as before, in the event of an increase in symptoms:

> *"Her job is supposed to stop people going into hospital and maybe I'm outside her remit because I know I'm going to go in as this bronchiectasis flares up again."* [70 – 79 year old man with COPD, Commissioning PCO]

Despite the fact that many respondents seemed quite positive about the growing number of professionals working in the community, closer to their

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homes, there were some who were unsure whether these professionals had the same expert knowledge as doctors at the hospital. Thus, patients who experienced the shift to the community through discharge from secondary care could feel let down having lost their access to the 'specialists':

"I mean if you've been going there for 20 odd years there's obviously a reason why you've been going there...and to just discharge you...I think, personally I think that that is wrong, because I've got nobody to speak to other than my GP now. I've got no specialist to talk to, I've got no specialist nurse to talk to." [50 – 59 year old man with asthma and COPD, Rural PCO]

"Perhaps it's because of my age and the fact that the position doctors and nurses had for the majority of my life, you know, and, you know, you sort of look at things and yeah OK, I mean a nurse is a well qualified man or lady whoever they are and they've had a lot of training and so on, but the doctor's done seven years to get his degree. Now how can they equate with the training that they've had and they're giving lots of things that used to be done by the doctor over to nurses and you think well are they really qualified to do that and I think that's always niggling at the back of your mind." [70-79 year old man with COPD, Merged PCO]

Others expressed frustration with the myriad of different roles which could cause some confusion, and in several cases were considered as additional layers that they had to painfully navigate in the quest for 'expertise' at the hospital level:

"I mean what's happened now in actual fact is, I think, that we're getting into an overkill situation we've now got the district nurse, the district respiratory nurse, the senior district respiratory nurse, the respiratory manager nurse.(...) How many more people are going to be a buffer zone with you and the doctors?" [60 – 69 year old man with COPD, Team PCO]

In this sense, many participants were quite perceptive of knowledge boundaries between the different roles and very aware of any changes that might have an impact on their access to professionals, who they felt had 'the authority' on their conditions.

Evolving professional boundaries and knowledge barriers

Several patients commented on how they felt that knowledge featured as a powerful tool within the hierarchy of health professions, and could be used as a determining factor in the marking of professional territories. Thus, community matrons were described as possibly clashing roles with respiratory nurses, or negotiating decisions about care with consultants, and GPs were sometimes depicted as needing to be careful not to *"step on the toes"* of consultants. Respondents' observations on nurses waiting for doctors' opinions before making decisions in care and doctors in turn making rapid referrals to consultants when unsure about the situation, demonstrated an understanding of knowledge barriers and mutual respect within the health staff arena. When it came to newer professional roles,

some patients respected the term 'specialist' and would even talk about their health professionals' extra training in respiratory care:

"You know, I mean she's a specialist, you know, I mean she's got the answers, she knows everything. You know, I mean the doctor doesn't really know, you know." [60 – 69 year old man with COPD, Team PCO]

"You know, and she's brilliant because when I was talking to her last time there'd been that programme on the TV with the London hospital, Papworth; is it Papworth? (…)Yes, so I think that's why she's very knowledgeable because she worked there before she came up [here]." [50 – 59 year old woman with sleep apnoea, Team PCO]

Others, however, expressed unease with the term 'specialist' being tagged on to roles; they were not entirely confident of the actual expertise that these titles denoted and were concerned that their care was being compromised:

"Is she, although they say, alright, she's a specialist respiratory nurse, she's not a specialist…they haven't made her a specialist doctor. So if, for example, we need to change my medication, should I be quite happy that she changes it for me without seeing the doctor? I don't know…?" [70 – 79 year old man with COPD, Merged PCO]

In some cases participants commented on how they felt their own knowledge was greater than that of some of their health providers, an aspect they found frustrating when they could not access the provider of their choice and had to either wait to be referred or see other providers they found less helpful:

"She wasn't the asthma nurse, she was a nurse that had tagged the word 'asthma' onto it. She knew much less than I did, you know." [60 – 69 year old man with asthma and COPD, Commissioning PCO]

"I was visited by my chest consultant, the first time I have been given access to a doctor who knew more about my condition and its treatment than me". [Extract from illness diary: 70 – 79 year old man with COPD, Commissioning PCO]

Other interviewees described how their providers recognised the wealth of patients' knowledge and actively encouraged them to make use of it.

Increasing emphasis on self-care

The majority of patients we spoke to were aware of the policy shift towards self care. Many interviews picked up on the shifting balance between patients and health providers who increasingly acknowledge patients' understandings of their own body and health and are happy to transfer some of the responsibilities over to their control:

"I have had people say to me, 'You know far more than we do', or, 'You know your chest far better than we do, so we should just leave it to you to sort out.'" [40 – 49 year old woman with asthma, Team PCO]

"If my breathing is not so good then the doctor's quite happy for me to increase that [inhaler] and to use that as and when required. […] I don't know if it's because I understand my complaint quite well and can manage it and seem to be responsible." [70 – 79 year old man with COPD, Merged PCO]

"They leave me with a stock, my consultant leaves me with a supply and they really leave the managing of the disease to my knowledge of how I am and if I know that I'm growing something horrible and it's a weekend or at night, I can self medicate." [60 – 69 year old woman with bronchiectasis, Rural PCO]

"I had a brilliant consultant who at that time was very keen for asthmatics to manage their own conditions so I was given two lots of short, sharp steroid courses to carry around with me […], so that I wouldn't have to wait and go and see a doctor or anything because he was saying, you know, if you get the steroids in quickly it, you get better quickly." [40 – 49 year old woman with asthma, Merged PCO]

"Now one nurse said to me: 'We like patients like you', because I was doing my own medication because I always do, I find if I don't I don't get it on time, and the first thing I do when I go in hospital is I sign a form that I'm going to self medicate. […] And they said: 'We like you, you look after yourself', I thought, well that's not what nurses are, you know." [60 – 69 year old woman with bronchiectasis, Rural PCO]

However, in the light of clinicians' encouragement towards independent management of the condition, many patients expressed a need for more advice on how to effectively engage in self-care and deal with everyday worries. They felt they were lacking professional guidance and suggestions on available resources that could be used to support self-management:

"These two ladies said that you've got some antibiotics indoors and steroids indoors, I've got them but it's interesting to hear how…I would like to do a bit more self help and some of the services out there…we're not all getting the information we should be getting. […] There's a singing group I wasn't aware of, there's exercise classes at the General…" [Focus group participant, Commissioning PCO]

Emerging new services

On a local level, participants generally perceived that their knowledge of developments and new initiatives in care provision was somewhat haphazard. In particular, knowledge of new local health facilities (e.g. local walk-in centres) seemed to be dependent on *"being around at the time"* and thus picking up on their existence either by walking by or through friends that had used them. As one focus group participant pointed out: *"It's not on a need to know basis, it's if you were here at the time"* to which another participant responded: *"If you don't know something, you don't know you don't know it"* [Focus group discussion, Merged PCO], suggesting some barriers to accessing information about local developments and new services. However, those patients who were able to access either pulmonary rehabilitation classes or other programmes seemed greatly to

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appreciate them and lamented the fact that they were scarce, quite difficult to get into and subject to increasing cut backs:

"It's very difficult to get on them; they're very scarce around the country. There's a number of rehab centres but…and it's run by a specialist respiratory nurse and the physio department and you go once a week for twelve weeks and you do various exercises, you have speakers come along and talk to you about the condition which is where I picked up most of the knowledge like that". [70 – 79 year old man with COPD, Merged PCO]

"I enjoyed it so much that I said to the respiratory nurse in charge can you only do this once, 'Yes you can because there's only, there are so many people waiting to go on it', so I was quite lucky really, you know, I didn't have to wait that long and I got on it and it opened up sort of a new vista for me, yeah, it sort of opened my eyes a little bit to it and all the things you can do to help yourself." [70 – 79 year old woman with COPD, Merged PCO]

"And the very place where you can get out, the day centre, after I came out from being an inpatient, you know, it's gradually being wound down and I found it so helpful, so useful." [60 – 69 year old man with lung cancer, Merged PCO]

8.3.2 Making sense of the changes

While most respondents made sense of their various experiences of changes in care in the context of financial cutbacks that dominate the current popular rhetoric on the NHS, often showing sympathy with the sinking morale of NHS frontline staff resulting from job instability and what they perceived were low salaries for nursing staff, others picked up on other underlying motives affecting health professional behaviour.

Financial cutbacks

In the interviews many references were made to the limited budget of the NHS and in some cases patients were suspicious that politicians were attempting to gloss over the reality of cutbacks. Interestingly several interviewees expressed sympathy and concern with the staff who they perceived as being *"overworked, underpaid and under stress"* and seemed more inclined to blame *"the system, the business"* for the problems in care provision. While many patients mentioned how they were generally satisfied with the services they accessed, others felt let down and expressed discontent at having had paid into the health services for years only to feel their care was compromised when they needed it. The most common reason that participants gave to explain the winding down of new services, the limited availability of service developments (like pulmonary rehabilitation) and the influx of new nurse roles in the community, was the financial constraints that they felt the NHS was experiencing:

"Went to relaxation class at [name] Centre at my local hospital. This activity is excellent and so rewarding. Like everything else in the NHS,

this service is limited due to lack of funding and lots of patients queuing up for weeks for treatment." [Extract from illness diary: 60 – 69 year old man with lung cancer, Merged PCO]

"Now there's a terrible shortage for those [pulmonary rehabilitation classes] all over the country and they keep asking the government for money to set them up. (…) So the physios don't get, you know, or the respiratory nurses are not given the facility because it's not made available to them and so on and so forth, and to me now that seems the right of everyone. You should be able to, in my view anyhow, go on it and have the opportunity perhaps of, alright perhaps not every year but let's say every other year if you want to go back and refresh on it and keep it up, but that doesn't happen.." [70 – 79 year old man with COPD, Merged PCO]

"I think so much is happening these days and so much is financially based you think to yourself, 'Hang on a minute, are they really qualified to take some of this work or is it just a financial get out?' We can't find enough doctors, so we'll say that some of these nurses are qualified enough to be able to do some of those things and it's purely a financial get out. And that's always at the back of your mind." [70 – 79 year old man with COPD, Merged PCO]

Nature of the condition

Despite the fact that many participants appreciated a general rise in awareness of the variety and nature of respiratory illnesses amongst the population, partly thanks to media coverage, some believed that respiratory conditions were still not being taken seriously. Several patients hinted at a link between the lack of provider interest in their condition and the nature of respiratory conditions, suggesting that they might be less fashionable for health professionals whose interests, they felt, might lie more in the instant satisfaction of a 'rescue' or in conditions they considered more 'in vogue' such as depression or cancer:

"…[asthma] is not very interesting is it? You rush in there from a huge car accident or a massive coronary, and then there is the psychological 'I can save somebody here'". [60 – 69 year old man with asthma and COPD, Commissioning PCO]

"I mean when I was first diagnosed with the COPD and I told you that they found what they said were nodules on my right lung and then they said they'd disappeared practically overnight and they said you've got COPD and it was basically take your medication, we'll see you occasionally and that's about it, you know. But then last year when my voice started to go and I was bringing up blood and then I was diagnosed with cancer the whole scenario and situation changed. They couldn't do enough for me, there was help and advice from different quarters, the respiratory nurse was available at anytime, you know, I could phone up and also the oncology department. So yes, there was a complete different outlook on the care." [60 – 69 year old man with lung cancer, Merged PCO]

"And the other thing of course is if, I don't know whether this applies at the hospital so much but certainly with the GP, if you were to go and say that, you know, you were depressed or you were going to have a breakdown all hell would be let loose and you would be seeing so many doctors and nurses you wouldn't know whether you were coming or going…because mental health services are so pushed." [40 – 49 year old woman with asthma, Team PCO]

New policies and arrangements affecting health services

Some patients who experienced what they felt were unjustified and confusing changes in their care, explained their experiences in the context of changing policies and new working arrangements. Thus a number of interviewees rationalised their discharge from clinics as due to policies on *"cutting the waiting lists by getting people out"* and others held newly established working arrangements responsible for their seemingly wasted time spent on having to repeat basic information on symptoms and biometrics:

"Why one should be asked all the same questions after being at the same surgery for 30 years is beyond me – and to measure for height and weight indicators. In the [newspaper] GP article says: 'Courtesy of the GP contract, there is more clogging up of medical notes, with measurements done for no good reason, except that the contract demands it, etc. etc.'" [Extract from illness diary: 60 – 69 man with asthma and COPD, Commissioning PCO]

Others, aware of changes in the way they had previously been able to book an appointment with their provider, explained their experiences in the light of new systems driving the changes:

"And the thing is they've changed the appointment system down there as well. Whereas you'd see the doctor and he'd say: 'Oh I'll see you in six months' and he'd put six months on the slip, you go to the reception and give that in and you would have an appointment there and then. They'll only give you an appointment now two weeks in advance."

Interviewer: *"I see, why's that?"*

"Well that's the new system that they've introduced." [50 – 59 year old man with asthma and COPD, Rural PCO]

Local and regional differences in care

Service users displayed considerable interest in and awareness of local differences in care provision. In a focus group discussion, participants expressed some distaste at the differing experiences of care within a particular location and used the term 'postcode lottery', which underlined their perception of haphazardness in accessing 'good' practices within their area. On a larger scale, several interviews also pointed towards patients' awareness of regional differences in care provision, either expressing advantages or disadvantages of living within a particular area. Experiences of care seemed to be a big topic in discussions between patients and their

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family and friends, who compared and contrasted the quality of services in order to map their own experience on the general perceptions of care country-wide. Several statements painted a somewhat disjointed picture of care on a national level:

> *"I mean you take social services and health services as a whole, I mean, are fragmented all over the place aren't they? And not only country to country but also region to region with all these, you know, health services, all these health authorities, I mean, so there is no generally, you can't really generalise over any of it, which is a bit daft really. It's not a National Health Service is it? It's a collection of regional health services."* [70 – 79 year old man with COPD, Merged PCO]

> *"And the other thing that I do know from talking on those sites is that in this country the care varies, well obviously that's why you're doing the research."* [50 – 59 year old woman with sleep apnoea, Team PCO]

8.3.3 Resources used to make sense of the changes

Many of the patients we interviewed gained their knowledge on the developments in the health services nationally and locally through newspapers and magazines, and also by discussing issues with friends, relatives or colleagues and through the internet and Breathe Easy group meetings. Clippings of newspaper items were sometimes appended to the illness diaries and many patients with access to the internet referred to websites they had used throughout the experience of their illness.

Local/ national media

While local newspapers provided some information on local developments, many of the headlines mentioned in the interviews related to negative media coverage on elder abuse in homes, patient experiences of neglect in hospitals, the fears connected with contracting MRSA and the financial cutbacks and their impact on care provision and benefits. Such newspaper reports enabled people to relate their concern to national events:

> *"And I have a local paper (…) and they say that the homes where I live here are absolutely a disgrace."* [60 – 69 year old man with COPD, Commissioning PCO]

> *"…and of course the other worrying thing now … is that recently in the press Peter Hain, the Work and Pensions Secretary, has announced that everyone on Incapacity Benefit is going to fail the medical. Now I've got a mobility car so I'm going to lose that and I'm really, really going to be stuck."* [50 – 59 man with asthma and COPD, Rural PCO]

> *"Wasn't it in our national papers, a 93 year old man who, committed suicide because he'd got to go in hospital and he was afraid. I can understand that, I can understand that."* [60 – 69 man with lung cancer, Merged PCO]

Internet

Those participants with access to the Internet sometimes found the amount of information overwhelming, but most comments were positive and provided insight into how this tool was being used to navigate the health system, gain insight into research on various conditions, access support groups and sites worldwide (in particular US and Australian sites) and fill in information gaps on details of the condition and possible treatments. Several patients also mentioned searching the Internet for official advice and guidelines when they felt certain aspects of their care (specifically monitoring) were being neglected:

"I'm sure it was the NICE guidelines, I'm sure it was NICE that said that the sleep apnoea clinics should be monitoring blah, blah, blah, I'm sure there's some guidelines." [50 – 59 year old woman with sleep apnoea, Team PCO]

"They are paid a lot of money to know about them. Everyone knows about NICE and I'm now in a different area and I've gone on the NICE website to find what the guidelines are to deal with the things that I'm dealing with so there's absolutely no reason a GP or respiratory nurse, they should know this stuff, they're paid to know it and that is what is so annoying. If I know it and I'm not a specialist, how do they not know it?" [Focus Group participant, Merged PCO]

Breathe Easy Groups

For some particioants, Breathe Easy Groups were greatly appreciated for their informality as a social gathering to meet others with similar concerns, for the opportunity to talk to health professionals outside the realm of the consultation room and for the leaflets and British Lung Foundation magazine which many patients valued. Their main appeal however seemed to surround the access to user friendly and useful information on dealing with respiratory conditions on a day-to-day basis and the access to professional insights into what was happening locally. However, few of the patients we interviewed had access to Breathe Easy Groups and some expressed little desire to attend. For some of these patients, this was because they saw no particular reason to attend, but others were deterred for other reasons including immobility, depression, or embarrassment about the condition.

8.4 Patient Involvement

"… we are passionate about our illness. We are! We're suffering from it and obviously we know what we would like to have and what we actually get." [Focus Group participant, Merged PCO]

In this section we present the data concerning participants' involvement in healthcare at both the 'patient' and 'citizen' levels. At the personal 'patient' level we examine the reasons behind self-care and the sources of support that patients described. We then explore what happened when patients deemed it necessary to access professional care: their methods of accessing and communicating with providers and the ways in which care was

negotiated, as patients participated in decision-making on treatment and medication.   As a final theme we present some evidence of 'citizen' involvement at strategic levels.

8.4.1 Self-care without professionals

> *"I don't have any care at all, I'm the carer."* [Focus group participant, Commissioning PCO]

Living with the condition

All patients we interviewed engaged in self-care on a daily basis, explaining how the condition was a constant part of their life and how it impacted on daily activities. Self-management, for many, began from the moment they woke up until the moment they went to sleep at night. Most respondents felt they had gained sufficient knowledge over the years of having to deal with their condition on a daily basis and avoided seeking medical assistance as far as possible as they were confident they could cope with the symptoms and did not think that professional advice could tell them anything they did not already know:

> *"I'm not somebody who will see the doctor for the sake of it, as long as my health is under control, I will keep well away from such people. […] I just feel it's a waste of time because I know what I'm doing now."* [60 – 69 year old man with asthma and COPD, Commissioning PCO]

> *"I don't use the medical services so much because, well not because they're anything… but I just, I don't feel as if I'm ill enough for that, if you know what I mean."* [70 – 79 year old woman with COPD, Merged PCO]

Several of those patients talked about how they were quite comfortable being left with the responsibility of their treatment, taking pride in being able to manage their medication independently, without too much input from health professionals:

> *"And usually sometimes, you know, when you're an asthmatic you know, well I do, I know when I need an antibiotic, I know when I need steroids and, you know".* [50 – 59 year old woman with asthma, Merged PCO]

> *"I do every now and again take a night off (medication) to see how I am and whether I really need it, I sort of trial myself."* [40 – 49 year old woman with asthma, Merged PCO]

Regaining control

In addition, many patients we interviewed commented on how they felt their identity had changed: the condition and its daily treatment had become the centre of their thoughts and was, to a certain extent, directing the pattern of the day and influencing moods and well-being. In particular, men perceived that their role as the *"man in the house"* had transformed, in some cases leaving them feeling emasculated and frustrated at seeing their carers taking over their previous responsibilities. Many women also

mentioned a sense of losing power within the household when they were left struggling with the activities that had previously been part of their daily routine and tasks. For some, self-care seemed to provide a new role and sense of control, a way of fighting back:

"I always get a sense of achievement when I do (pulmonary exercises). Must be good for morale." [Extract from illness diary: 70 – 79 year old woman with COPD, Merged PCO]

"I feel as though I'm hitting back somehow which makes me feel I can do something." [60 – 69 year old woman with bronchiectasis, Rural PCO]

Avoiding medical care

In a different light, several interviewees who managed their condition independently provided reasons that seemed less indicative of their pride in being able to deal with their condition or a way of fighting back than of their desire to avoid seeing health professionals, who they sometimes perceived as having limited time, little empathy and little patience. Strategies used to avoid professional help included home remedies to alleviate symptoms, massages and other alternative therapies people found on the internet or heard about through friends and relatives. Even when symptoms seemed to get more severe, some patients described how they would persist in self-care, unwilling to arrange a consultation with a provider:

"If I was poorly with my asthma, if I could stay at home I'd rather stay at home, absolutely." [40 – 49 year old woman with asthma, Merged PCO]

"I don't like to bother people, you know, I'll kind of struggle on and struggle on until I'm, you know, desperate really before I bother them." [40 – 49 year old woman with asthma, Team PCO]

Similarly, resistance against going into hospital emerged as an important aspect in the discussions about self-care. Even those suffering severe symptoms resulting from their condition would try and circumvent a hospital visit, going as far as openly negotiating with ambulance staff who had come to take them to hospital. Being able to stay within one's own familiar surroundings while administering medication, avoiding impersonal care, the possibility of contracting MRSA and not wanting to have to deal with uncommunicative hospital staff, were all mentioned as reasons for preferring independent care at home:

"They [staff at the hospital] just do their business and it's like no partnership, they do the business and it's goodbye, thank you very much and you're out the door. There's no sort of can I ask a question on this or can I ask that, maybe I've got that wrong, maybe they might be entirely different after you've visited them several times but I don't think they are because everybody seems to be waiting in the queue and impatiently, you know what I mean? You daren't ask questions […] they think you're being nosey or enquiring and it's not for you to learn and for

you to think about the works of your body." [60 – 69 year old man with COPD, Commissioning PCO]

"Everybody is so busy and they don't have time to tell you at whatever level is the one at which you understand what they're talking about." [70 – 79 year old man with COPD, Merged PCO]

8.4.2 Sources of informal support in self-care

Support at home

In the daily management of the condition, participants mentioned several sources of support that they could access and greatly valued, conscious that they might not be able to deal with their illness without them. Hence, support from spouses or other family members acting as carers was mentioned as indispensable and central to many patients' lives. Carers were described as providing transport and thus some access to the outside world, ensuring a regular, stable routine to life, and helping out with medications. They were frequently praised for their capacity to ensure patients' emotional well-being. Consequently many of the people we interviewed who had carers considered themselves very lucky and were greatly concerned with their carer's welfare, worried about how their illness could affect their carer and keen for their carer to be seen by health professionals from time to time to ensure their good health and well-being:

"Fortunately my carer, who is my wife [...] soon shakes me out of my blues. I would be lost without her and her kindness and thoughtfulness." [Extract from illness diary: 70 – 79 year old man with COPD, Merged PCO]

"I could not remain in our home without him (the husband), he is my transport and "in house" honorary medic!! So says my GP." [Extract from illness diary: 60 – 69 year old woman with bronchiectasis, Rural PCO]

"This is a problem really not about me but, you know, I've got a problem health wise and it's, you know, me but it affects [my wife], you know, and I think people, I'm OK but people don't acknowledge that there's not one patient but two and they've got to look after the partner as well or who's doing the caring and one thing and another because it's very, very difficult for her. And OK, we can get some help I know that, you know, but I know maybe somebody else can't, you know, and it's very important that they're looked after, you know." [60 – 69 year old man with COPD, Team PCO]

Information and guidance

When it came to advice and information needed to engage efficiently in self-care, many patients demonstrated resourcefulness in researching and finding out about their illness. Patients who were confused by their communication with health providers or had little trust in the consultation and advice, would additionally seek information and advice on dealing with

the condition from Breathe Easy Groups, books or journals on the condition, relatives and friends and the internet, thus creating a network of knowledge sources through which they could compare and validate their various inputs of information. For those with access, the internet was specifically appreciated for its wealth of information on treatments, new medications, worldwide research and developments. Many respondents described how they wanted to discuss these insights with friends, relatives and those health providers who were open to discussion. Others used the internet as a means of communicating with patients suffering from similar conditions and found support particularly from American support websites which provided the possibility of exchanging experiences and discussing thoughts through virtual web groups:

> *"So in the early days I got a lot of support on the computer, I went onto mostly American chat sites, not chat sites but sleep apnoea sites where – and you read all these people what they're saying and it's so the same, it's so all the same feelings and thoughts and then you might put your little problem in and then they would email you and support you, so I did get a lot of support from total strangers."* [50 – 59 year old woman with sleep apnoea, Team PCO]

Other interviewees, however, showed hesitation in exploring their condition independently, as the thought of finding out bad news outweighed the desire to discover anything new:

> *"I don't particularly want to know, you know, I prefer not to know. I don't want [to be] thinking about it to be quite honest. I bury my head in the sand, but I prefer to be like that"* [60 – 69 year old man with COPD, Team PCO]

While some people we talked to were relatively happy with the level and type of non-medical support they accessed in order to effectively self-care, others felt that the sources of informal support were not sufficient for them to feel comfortable in dealing with their condition. Hence patients who were aware of waning provider involvement in their care if they seemed to be managing too well, expressed concern when they felt nobody was checking up on them from time to time. Hints of feeling somewhat abandoned and left to one's own devices without sufficient regular professional input surfaced in several interviews:

> *"… I said, 'Well why are you only seeing me every month or two?' 'Oh well, you always seem to be able to manage'. And so well, I can, but should I be, should I be just doing it all on my own, do you know what I mean? I don't know the more independent and able to manage you are the less keen they are to see you sometimes."* [40 – 49 year old woman with asthma, Team PCO]

> *"I can't be too bad because nobody is bothering to check on me. Really I suppose thinking about it…It's not a very good situation is it, because it means that I will only get somebody checking on me when I am very ill, when I have a bad infection."* [70 – 79 year old man with COPD, Merged PCO]

8.4.3 Moving towards seeking professional care

When to seek medical advice

Access to clinicians became particularly important in dealing with unexpected exacerbations of the condition. In the discussion about the appropriate timing to seek medical advice, there seemed to be two main opinions. Some participants, those who felt they knew their condition well enough to gauge whether or not they needed to contact a health provider were relatively comfortable with the management of their disease and their knowledge of when to seek medical advice. Some of them spoke about being able to detect changes in their symptoms that clearly signalled the boundary of when to cease self-care and seek professional help. These patients also communicated their trust that if they did have a sudden worsening of symptoms, they could immediately get in touch with a professional who would provide support:

> *"I self medicate. […] I have the face mask etc and also the nebules and everything else that I can connect up to my oxygen container. The taking nebules and so forth… it's only after I've taken all those that I can then ascertain my own ratings as to whether I'm winning or whether I'm not. It's at that stage then that I would actually say well I need an ambulance or I'm going to be alright just leave me alone for an hour or so you know."* [60 – 69 year old man with COPD, Team PCO]

> *"If I'm having a bad breathing day which you can have for no apparent reason, you can be quite good one day and the next day you're having a difficult day. I obviously have to sort of monitor my own sputum from that respect and I can tell from that now after all these years do I need to go and see the doctor or am I just having an off day."* [70 – 79 year old man with COPD, Merged PCO]

> *"I know if I have any worries, I just have to ring him. If my peak flow gets below 300mg, I ring straight away".* [Extract from illness diary: 50 – 59 year old woman with asthma, Team PCO]

Other respondents spoke about how they were anxious about not being able to recognise warning symptoms and articulated their insecurities as when to seek professional help. They were worried about being left to their own devices without being seen by a provider on a regular basis who could then detect if something was not quite right and needed medical attention. For many of these patients, the condition felt somewhat unpredictable and difficult to control without some monitoring:

> *"Well normally as I say to people the main problem with it is that I don't know when I'm ill, because you go down a little step each day and, you know, it's hard to say when you've reached the point where you want some treatment, you know, apart from the normal medication I'm on naturally."* [70 – 79 year old man with COPD, Commissioning PCO]

> *"I don't really know what to do in a way, you know, because the nurses say to me take your medication and they then say to me if you feel worse then just ring them up. But it's like it all the time so it's no good*

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you ringing every time, you know, I get out of breath, it's very hard to get through with it." [60 – 69 year old man with COPD, Commissioning PCO]

The importance of reassurance

In general, all the participants, including those patients who showed confidence in their abilities to cope with their condition, talked about how they would appreciate some kind of support or regular contact with providers in order to feel comfortable with managing their condition. They suggested that this might take the form of occasional phone calls to ensure that the condition had not deteriorated and that they were *"doing the right thing"*:

"I find now although I've been saying to you that I know how to control the asthma and so on, the drugs and so on what I have got very confused by is that actually the recommendations have kept changing […] It's probably because I'm getting worse and older but it would be nice actually to be able to email somebody like her [nurse] as well and just sort of say…remind me of the procedure of coming off a high steroid…" [50 – 59 year old man with asthma and COPD, Team PCO]

"And I've tried to sort of say look, you know, I mean I'm not really very needy I've got lots of friends and stuff, it's just somebody to know what drugs I'm taking, just somebody to maybe, you know, give me a ring once a month and say are you OK, how you doing, you know, what's happening, how are you managing, are you all right, that's all, not any more than that." [40 – 49 year old woman with asthma, Team PCO]

"It would be very nice to know that somebody in actual fact is keeping a tab on you". [60 – 69 year old man with COPD, Team PCO]

As these quotes illustrate, the possibility of accessing a provider apart from the motivation to get medical advice, but also for some reassurance, appeared to be very important for many patients. Despite the fact that many interviewees described the support that they got from talking to friends or relatives, patients also mentioned how they did not want to cause concern or sometimes felt a lack of understanding for their symptoms when talking to lay people. The beneficial impact of speaking to a professional, however briefly, was sometimes mentioned as a great asset for those who did have a good relationship with their providers:

"And I just think if you can speak to a doctor sometimes it will make you feel better and sometimes you can feel lousy, really lousy but you can go to the doctor and when you come out, even if he ain't really done much, if they've said well, you know, 'You'll be alright in a couple of days', you automatically feel better, and I think, perhaps it is psychological I don't know but I do think you automatically feel better just maybe talking to someone on the end of the phone, I mean even if it ain't a GP, the nurse." [50 – 59 year old woman with asthma, Merged PCO]

The need for flexible access

Many of the responses suggest that independent self-care is appropriate *"as long as you know what you're doing, as long as you're happy"*. Generally it emerged that a higher comfort level in self-care was achieved when patients felt they had the necessary professional back up to rely on. As one patient put it, self-care seemed to work most effectively if the access to a trusted health provider could be flexible and according to need:

> *"You know, and the thing there is that it's a peculiar feeling. You want somebody to be there, but you want to be left alone, if you can understand what I mean. (...) it's nice to know that there's somebody there if I need them, but I don't need them until I shout, you know?"* [60 – 69 year old man with COPD, Team PCO]

Consequently, several patients whose providers had encouraged regular communication and provided support when needed appreciated the security and continuity of care that this type of contact could offer. Many patients mentioned how they valued the availability and option of provider involvement at varying flexible stages throughout the management of their disease:

> *"He said if I have any problems just ring either him or the nurse up and they would sort it out, which I knew I could do. [...]Yeah they're really good."* [50 – 59 year old woman with asthma, Team PCO]

8.4.4 Communication across the boundary

Enabling factors in communication

Patients recognised several factors that influenced the communication with their providers and which had an impact on the responses they would get from them. Thus some mentioned characteristics such as age, educational background and traits that underlined confidence and assuredness as potential advantages in the negotiation process:

> *"I've generally found that with the doctors is if you, if they realise that you're obviously educated at least to their level if not higher and you ask sensible, you know, sort of adult questions or you – it depends on the doctors. [...] I mean that's probably another thing I find because I'm 62 now so I'm not some young whippersnapper asking them questions. Because I also believe that you shouldn't accept blindly what they tell you, you should ask them questions. [...] I think that aspect is... being able to ask questions and asking them a sensible way and the consultants sort of think oh well he's another graduate, university educated like they are they're more prone to be able to talk to you."* [60 – 69 year old man with sarcoidosis, Merged PCO]

A solid relationship built up over time appeared to be the most important factor influencing and encouraging good communication between patients and their providers, and this issue is considered next.

The importance of a relationship

The majority of participants seemed keen on building a good relationship with one health provider, who they could then access on a regular basis by visits, phone or email. Terms such as 'mutual agreement', 'partnership', 'working relationship' 'trust both ways' and 'confidence' were used to describe some of the interactions between patients and providers, underlining the appreciation of open communication, shared decision-making and mutual trust. Many patients expressed the need to be taken seriously by their providers, not only when it came to describing their symptoms, but also when it came to discussing research on medication they had found or relevant items in the news or on the internet about their condition. Patients who felt accepted as real partners in their care rather than mere recipients seemed more content with managing their care independently if they felt their treatment pattern was a result of a decision they had partaken in and if they felt they had the backing of a good relationship and the possibility of discussing their findings and thoughts if needed:

> *"Telephone conversation with GP [name] re result of increasing steroids. As usual a discussion rather than a tell/listen session. […] Value relationship with GP very much, adult-adult rather than adult-child in transactional analysis terms. Treatment by agreement rather than imposition. Similar approach with Dr [name] at hospital from the beginning."* [Extract from illness diary: 60 – 69 year old man with sarcoidosis, Merged PCO]

> *"He (the GP) really put his mark on the practice. You could talk anything through with him, whatever it was and you always felt that when you left him you'd come to a mutual agreement. That either he would say 'No, we can't go down that path' or 'Well, if you want to give it a try'".* (70 – 79 year old man with COPD, Commissioning PCO)

> *"We use the email sometimes, if I'm going to see him I'll email him and tell him why I'm coming so he can check into anything that's necessary and so on and I think we have a good working relationship."* [50 – 59 year old man with asthma and COPD, Team PCO]

Barriers in communication

Despite the importance attached to creating and maintaining a good relationship with their health providers, some patients hinted at difficulties in ensuring a good rapport. The interviews suggest that open and honest communication between providers and patients could be a challenge during the consultation, and provided interesting insights into some of the limitations for patients of being 'partners' not 'passive' recipients of care. Apart from language barriers which sometimes made communication difficult, particularly with health staff from abroad, other remarks were made that illuminate the subtleties of behaviour occurring in the interaction between patient and providers that hindered and shaped the process of communication.

Being a good patient

On the patients' side, several comments suggested that the fear of not being seen as *"a good patient"* prevented some from being frank with their providers. Thus some patients remarked on how they would try and keep a brave face in front of their health provider, worrying that if they were perceived as *"whining"* like a *"Droopy Doris"*, medical staff would not respond well. In several cases, interviewees even mentioned how they avoided making demands or complaining altogether for fear of more serious repercussions risking the quality of their care:

> *"I have great fear that if you make any noise and cause trouble, then your name is ticked and I think you'll be treated badly. You know, that's what I think anyway, you know, don't make a fuss and everything will be fine".* [60 – 69 year old man with lung cancer, Merged PCO]

> *"When you're in hospital they are – if you upset the nurses, God help you, you know, even the ones that aren't nice to you, you've got to be nice to, otherwise you're not going to get anybody coming when you ring the bell and I think that's what's letting the health service down."* [60 – 69 year old woman with bronchiectasis, Rural PCO]

Providers' language and reactions

On the providers' side, respondents sometimes perceived health professionals' reactions and responses to their queries and need for clarifications as less than encouraging. Several patients mentioned how they felt excluded from the discussion of their condition, due to the language professionals used in consultations, leaving many struggling with medical jargon and expressions. Several of the interviews also describe situations in which patients had tried to discuss items they deemed important for the management of their care with providers but were met with little interest or tolerance:

> *"Well, I did discuss it but they are not really interested. I mean when they see you are not dying and you make all these suggestions they always look at you as if you've been spending too much time on the internet…"* [60 – 69 man with asthma and COPD, Commissioning PCO]

> *"I think my experience [is that] we as patients are not to have that knowledge of, you know, what is wrong with us and I, you know, I don't like it when you are in fact in a hospital and a group of doctors will come and see you and ask you questions and they all walk away and then they have a little chat about you that you can't hear."* [60 – 69 year old man with lung cancer, Merged PCO]

> *"I mean the last time I saw the consultant I asked him a couple of things that I'd read and one was that in Australia they believed that singing strengthens up the part of your throat that collapses with sleep apnoea and they also believe that playing a trumpet or playing a [didgeridoo]. They believe that that is helping and I asked him and he just totally*

didn't want to hear from it, didn't want to know." [50 – 59 year old woman with sleep apnoea, Team PCO]

Similarly, other interviewees who had been encouraged by professionals to self-care and mindful of what they had picked up from the Expert Patient Programme or pulmonary rehabilitation, found the recommendations made in the schemes quite difficult to follow in the 'real' context of a consultation, particularly if faced with a healthcare professional who was not open to questions and discussion:

".. You really need to be careful to ask as many questions as you can remember to do at the time. Expert Patient Plan – there's a list of questions you should ask your GP or consultant, you know, what does this drug do? Why do I need it? But I find it's quite hard to remember to do all that when you're sort of, you've got to somehow feel… what's the word…it's not really under pressure but you feel threatened by these consultants that you don't really know…It's quite difficult sometimes to pick up the courage to say 'Well wait, why do I need this?' and 'Is it the only option?' and so on and so on". [50 – 59 year old man with asthma and COPD, Team PCO]

"I just completed a pulmonary rehabilitation course at the hospital and I sort of learned a lot from them, and also that I don't complain enough. Yeah, little things like you should always have a supply of steroids and antibiotics in the house and your doctor should be able to do that for you, you know. And they gave us a form to give to the doctor, which I did because I had a chest infection a few weeks ago and he just sort of looked at it and sort of put it to one side, you know, and said 'Well we'll think about that'." [70 – 79 year old woman with COPD, Merged PCO]

Patients also recognised the impact they had on clinicians' behaviour if they seemed too knowledgeable and informed. Several participants commented on how they thought their healthcare professional might feel threatened or uncomfortable with them being too knowledgeable about their condition. As a result some patients recounted how they had tried to play down their insight and understanding of the condition:

"Maybe they feel threatened sometimes doctors, you know, if their knowledge is… or maybe they feel threatened that their knowledge is going to be challenged or that, I don't know." [40 – 49 year old woman with asthma, Team PCO]

"Well I'm very sort of tactful about it because you can see them getting quite, you know, he shouldn't be asking us questions and answering them at the same time, you know, so one tends to, you know, keep quiet about it, so it's really a question of knowing exactly what works and just demanding it." [60 – 69 man with asthma and COPD, Commissioning PCO]

In spite of the unease some clinicians demonstrated when confronted with knowledgeable patients, knowledge emerged as an important factor for many patients who emphasised the importance and value of their input into the decision-making process on their care.

8.4.5 Negotiating care beyond the boundary

The amount and type of knowledge patients had about their condition seemed to give many a sense of power and thus a valuable asset in the negotiation process with clinicians. As a result, several participants illustrated the different ways in which they sometimes bargained over their medication intake and treatment patterns. Some patients described how they initially had taken a more passive *"back seat"* approach, letting healthcare professionals dictate care and then when confronted with problems or lack of response, would become active enquirers, investigating treatment methods and providing ideas on how their care pathway could be improved. In some interviews, patients even hinted at their superior knowledge to clinicians who they sometimes felt lacked the experience and expertise in their condition. The majority, however, recognised their knowledge limits but greatly appreciated it when they felt that their concerns and suggestions had been taken into account and that they had been part of the decision-making process:

> *"Yes, because it's like anything medical it's your body and you know your body better than anybody else and you know your body how it responds to different medications better than doctors, you know, if you feel that medication is making you feel a certain way or unwell then you tell the doctor and, you know, you make them listen."* [60 – 69 year old man with lung cancer, Merged PCO]

> *"I mean I found at the hospital I argued about not going on steroids but they just accepted my arguments at the time and said alright let's see what happens and so I put off taking them for six months or more until I lost more lung function and then they said right it's getting so bad you're going to have to do something and I said alright then. So in that respect they'd taken account of my views on the treatment."* [60 – 69 year old man with sarcoidosis, Merged PCO]

Conversely, some respondents preferred less negotiation and more input from their clinicians, with a clear division of responsibility. Patients who were not comfortable with expectations on them to participate in the decision-making process of their care made clear the limits of their knowledge and expressed discontent with health professionals who they felt were asking too much of their opinion. They felt that they had dealt with as much as they could within their capability and now needed expert advice:

> *"You've gone to them and said 'I need your help, I can't deal with it, I want you to make me better'. That's their authority from my point of view, to tell you what to do. […] I mean nowadays it's well 'What do you think about it?' and you know, the answer really is 'Well, I don't know, that's why I've come to see you… because you're the expert!'"* [70 – 79 year old man with COPD, Merged PCO]

8.4.6 Involvement at other levels

Despite the fact that the main bulk of our data suggest that patients are primarily involved in personal elements of their care, i.e. in managing their

care needs and their access to providers, there were also some examples of patients getting involved at other levels of the health system.

In some cases clinicians had encouraged their patients to talk at Breathe Easy Groups or to speak about their experiences dealing with the condition with other patients in hospital settings. One patient had gone a step further and described how he had tried to start up his own support group for diabetes from the backroom of a restaurant after several other patients lacking support had approached him for ideas. Despite the fact that they could not find health professionals to come and speak at their meetings, the group continues to meet from time to time, mainly for emotional support and *"to have a laugh"*. Another described her involvement in schools talking to teachers about children with respiratory conditions:

> *"It was a course about what you can do with asthmatics and what you can't do and how to administer the inhalers and what inhalers should be in schools […] and then we'll get a certificate to say we're asthma friendly and we can deal with this and deal with that."* [50 – 59 year old woman with asthma, Merged PCO]

Several participants described their attempts at disseminating useful information and advice that they had discovered through their own search for ways to deal with their condition. Apart from sharing their insights with support groups, their health providers and other people suffering from the same condition, several also tried to contact people at higher levels in the NHS or political structures to inform them of useful information they had discovered:

> *"I told the doctors at the hospital and also my GP and they were all very, very interested and I've supplied them with literature and DVDs and copies of the book and I even wrote to the Secretary State for Health, the Prime Minister, to local MPs asking if research could be done into fibromyalgia."* [60 – 69 year old man with lung cancer, Merged PCO]

There were also some examples of how patients, who had experienced an unexplained change in their care patterns and felt let down by the health system, took the initiative and contacted their local representative, who they hoped could have an impact on the elements of care they were lacking. Interestingly, none of the patients in our study mentioned the campaigning and lobbying role of the British Lung Foundation or Asthma UK in this context:

> *"Wrote to MP, and consultant at the hospital re. lack of portable cylinders."* [Extract from illness diary: 70 – 79 year old man with COPD, Commissioning PCO]

> *"Made appointment to see [my MP] to complain about being discharged from the chest clinic."* [Extract from illness diary: 50 – 59 year old man with asthma and COPD, Rural PCO]

In addition, patients' motivation to participate in our study indicated an interest in being involved and taking part in shaping and developing the health system.

8.5 Conclusions

The patients who took part in our study not only demonstrated high levels of awareness of changes in their care and local and regional developments in the health services, but showed great interest in the causes behind what was happening. Their methods of getting involved in their care reached beyond the mere engagement in self-management of their condition but also included involvement in local activities and initiatives in ensuring adequate provision of care.

Against this backdrop it is interesting to look at providers' perspectives on involving service users in healthcare. The next chapter thus picks up on the theme of patient involvement and provides some insights on professionals' thoughts and opinions on involving patients.

9 Professionals' perspectives on involving patients

This chapter draws on data collected in phase 1 and phase 2 of the study that relates to professional attitudes on involving and engaging patients.

9.1 Summary

Although we had not specifically explored the perceptions of interviewees in phases 1 or 2 about involving patients, many interviewees discussed issues related to how health professionals thought about patient participation in the planning of services.

Patients were described in their potential roles as members of local development teams, as consumers with the possibility of feeding back their views and opinions of existing services through questionnaires, as tax payers and thus the main funders of their care with decision-making power when it came to service reconfiguration and as partners in managing their care.

In general there was a sense that professionals were keen to provide patient-centred services, were interested in patients' opinions on existing services and welcomed the insights that patients brought to discussions about service development.

However, professionals also highlighted the difficulties and barriers in involving patients, in particular, questioning how to ensure representative views, and were aware of the danger of initiating participation without being able to adequately address and include patients' views when it came to the reality of changing aspects of health services.

9.2 The patient as a member of the team

Although most interviewees acknowledged the importance of the patient's voice being heard, and frequently emphasised that services were being developed to *"make services best for patients"*, only three described having a lay member actively involved in their local development team, and one of those had recently resigned and not been replaced:

"We worked as a team really....We had patients, we had consultants, we had respiratory nurses, dieticians, occupational therapist, we had the discharge co-ordinators, there was the ambulance, there was the Social Services. So, there wasn't one particular individual. We worked as a team to deal with that." [PCO 9: respiratory nursing team, Interviewee: Service development manager]

"I think you need clinicians who are involved in the field, I think you need patients who've got the problem, I think you need carers who manage the problems, I think you need nurses who see the problem on a fairly frequent basis, I think you need some sort of background information person to deliver the information we require and you do need a manager but they should be in relatively small numbers and they shouldn't be developing the overall strategy". [Rural PCO: Respiratory consultant]

The support of patients was seen as an important asset in negotiations for funding, and indeed, sometimes a pre-requisite when compiling formal bids for service development:

"We also want to get a patient representative on it as well because I think that's important, again it's an ally, you need your allies because at the end of the day it may not be [possible] but if a patient stands up and says 'I think this is wonderful, I think this is great', it's got to make a difference." [Team PCO: Respiratory GPwSI]

"I think the other aspect about this, you know, if we get difficulties with the Trust....I think having patient representation is, you know, excellent and whether it's someone with COPD particularly or whether it's just someone that, you know, would wish to serve, ask difficult questions, both of us and the Trust." [Team PCO: Manager]

"We haven't had quite such a level of patient involvement at the present time but the orthopaedic bid certainly will need to. They will have to involve the public in what they're up to." [Merged PCO: GP]

The presence of patients in the discussions about service development was seen as a possible mechanism for overcoming a difficult situation between primary and secondary care as (hopefully) both would unite in the face of patient preference and need:

"Yeah because I know obviously, you know, we've got the issues between secondary care and primary care and I think it'll be a sort of a big learning curve for me...and I think it might be different if we have patients onboard, whether it will or not, it will be something interesting to see." [Merged PCO: Manager]

As well as needing a *"culture change"*, a number of practical issues were identified that could act as barriers to involving patients. These included inaccessible meeting venues, medical or health service jargon in documentation, the professional time involved to ensure patient involvement and the potential load on user groups:

"My worry is that we'll end up with different groups for different conditions which is difficult to manage but if we had a reference group, and I know this again is coming from Strategic Health, like diabetes they've got a reference group that feeds into Strategic Health which is people from across the country and whether from different PCOs it would make sense to me that we had sub groups that again fitted into that so it all fed in together." [Merged PCO: Clinical manager]

"It's such a challenge. You're faced with the dilemma of having patients come and sit bemused at meetings not fully understanding what's going on or going to patient forums where there's sometimes not the deep understanding of what's going on." [Team PCO: PCO manager]

In addition, the representativeness of involving one single patient at a meeting was questioned as professionals pointed out that an individual could not speak for the general public and often those patients willing and able to participate were those less severely debilitated by their condition.

Respondents expressed concern about the risk of involving patients merely in order to fulfil the criteria:

"My worry is we .. tick a box that Joe Smith is there but is Joe Smith going to have, you know, will he speak on behalf of the community or will he speak on behalf of himself?" [Merged PCO: manager]

"So, involving patients. It sounds easy. It isn't. I mean sometimes my experience of involving patients is you wish you blooming hadn't even started it in the first place, because if you get one person they bang on the drum about their own plight or experience and that's not the same for everyone. You don't want to just be talking so you can have, tick that box that you have a patient on your committee because that doesn't work either. And then these big conversations that we have, you know, you find the people with the loudest voice. They won't be the people with COPD because they're often too frightened to leave the house to come and have the big conversations, that's the problem." [Team PCO: PCO manager]

9.2.1 The patient as a consumer

A more common approach was to seek patients' views on existing services (for example with satisfaction questionnaires or complaint forms) or on preferences for redesign (for example with 'discovery interviews' or by engaging with an existing local interest group) and feeding the insights gained back to the professional team. One limitation was that people living in isolated communities might have little insight into the quality of services and possible service developments in other parts of the country:

"What you tend to find is the patient in the discussion with an independent person will often say what all the problems were and they'll come up with the solutions, so that sort of information was discussed with the staff as part of the pathway development...OK that doesn't work, it's not good for patients for all the reasons that patients have said. What would be a better way of doing it?" [PCO 10: respiratory nursing team, Interviewee: Nursing manager]

"I think it's a way of putting ourselves into where the patient is, and one of the things which we want to do is to actually get patients who've had experience of [going] through the system and speaking with them and getting their story basically to see what their experience is like. Because I think that's very important because you can always set up lovely, nice flowcharts that look very nice on paper but for the individual it doesn't always match reality. And I think that's something that we've got to learn and it's trying to introduce that." [Team PCO: Respiratory GPwSI]

"The inner city area has got a high Asian minority population but we have got an excellent public involvement manager involved in quite a numerous amount of projects within the inner city. And we've got good engagement from those minority ethnic groups. That's about it really." [PCO 22. respiratory nurse service with consultant outreach. Interviewee: Service development manager]

"I mean the other thing I'd say about my patients is they don't, well how do they compare with anything else, because most of them have lived in [area] all their life. They don't know any other practice and they might think we're rubbish, in fact we might be good or they might think we're wonderful and we might be rubbish so they can't tell." [Rural PCO: GP]

Our interviewees often made assumptions about patients' priorities (for example: *"I think it's mainly to do with transport"* or *"I think that [achieving targets] has been greatly reassuring to the patient and improved their quality of life hugely"*) though others recognised that it was important to ask patients personally. Clinicians valued informal feedback on the service they were providing, and were often cast in the role of patient advocate, advising on what would be best for patient care:

"I think I have to remind clinicians that we have to think of what the public's needs are really and a lot of it is assuming that patients are happy with the service. Well, are they happy? Have we asked them are they happy? You know, we're thinking they are, but actually could it be better than what it is?" [Merged PCO: Manager]

"And apart from that which is very, very, it is very, very important I think ultimately it's nicer for the patient too because they feel, you know, the feedback I have from the patients is always very, very positive and, you know, it's almost like an instant feedback." [Merged PCO: Community matron]

Other respondents described the difficulties in ensuring that patients' comments and opinions on services were captured and adequately addressed at different levels of the system, thus indicating that taking into account patient experiences and dealing with patient complaints may feature low on the priority list:

"I don't think it's high enough on anyone's agenda, the patient experience. They give it lip service but I've yet to be convinced that what patients say and complain about has much influence. I know the Chief Executive will write a letter and there'll be an investigation and patients will be written to and, you know 'Thank you very much, we're so sorry you had that bad experience', but I'm not sure how much it changes." [Team PCO: PCO manager]

Several interviewees expressed the concern that there was a perverse risk of patients being used as pawns in a game, rather than as consumers with choice. Examples given were in the context of hospital trusts admitting patients to maintain income streams, or respiratory nurses thwarting plans to allow community matrons to take over aspects of their role:

"I think it's very difficult to turn the vision into a reality that works for patients and the people who lose out in the end in all of this are the taxpayer and the patients because in the end they are being shunted around, they may think they have choice, we may be giving them a bit of choice but in the end they are still being shunted around to suit bigger agendas, I guess that's my preach for the day." [PCO 3: GPwSI-led team, Interviewee: Commissioner]

"I mean I personally feel, and I say this quite publicly, that Practice-Based Commissioning and Payment by Results set two groups of people against each other in search for a pot of money and the question I have to ask is we seem to be forgetting, you know, should we ask actually what's best for the patient, which is the best service because patients actually – just think we're all employed by the NHS, which ever building they see you in it's not relevant to them who employs you, who pays the budget, you know." [Merged PCO: Specialist respiratory nurse]

9.2.2 The patient as taxpayer

Some interviewees described the patient's role as the funder, via their taxes, of the health service and the person to whom they therefore owed a duty to provide cost-effective safe care. Decisions about reconfiguring services, especially emotive issues such as reducing community hospital provision, were therefore seen as being appropriately in the public domain:

"And I met with our information people recently, because I want a performance framework for every clinical service I've got, because I think it's very important that we prove their worth, because it's public money we're spending, actually, and my view is, that [available data], doesn't tell me if we're spending public money wisely, if we're getting best value for money." [PCO 7: respiratory nursing service, Interviewee: Nursing manager]

"Well at the end of the day you've got to use your pot of money to the best advantage of the patients and the only difference is peoples' views of how to spend it." [Rural PCO: GP]

"…and you've got to be able to reassure the public that what you're giving them is not necessarily a second rate service but a service that is more efficient and is allowing people appropriately trained to deal with more difficult subjects in hand" [PCO 14: GPwSI service, Interviewee: GPwSI]

"…There will be some change, but I think people are very aware of it now, I think they really are and I think there are more local hospitals certainly at [town], there's a lot of talk about that, what's going to happen to that one in [town]. People now are sort of becoming much, much more aware of what's happening and they like to keep their services more local, you know, they don't like to see things go. So yes it is, it is interesting, I have to say, I mean I think more so now than ever people seem to be a lot more aware, it's on the news more, it's in the local press, and sometimes things come out in the press before we even know about it, you know." [Merged PCO: Community matron]

9.2.3 The patient as a partner in managing care

Self-care, often in the context of the Expert Patient programme, was described by many interviewees as an important aspect of their long-term condition strategy which could *"allow patients to take ownership"* and *"reduce the dependency culture"*:

"It does fit in quite well with some of the strategies around long term conditions around, you know, empowerment and education and expert patients, so we're trying to sort of tie it in with those sorts of initiatives as well, so that patients and their carers get involved in some of the ongoing education sort of support etc. so…and they self manage better." [PCO 15, respiratory nursing service, Interviewee: Service development manager]

"I'd like to think that we can develop a patient forum in due course, rehab programme, COPD Expert Patient Programme. A whole range of things we can do that we found in [another locality] has really helped the patient to look after themselves to a great extent." [Rural PCO: Respiratory consultant]

A number of interviewees highlighted the importance of developing a professional/patient relationship as an important basis for enabling self-care and gaining a better understanding of the variety of patients' needs while dealing with their condition on a day-to-day basis. Trust worked both ways: patients needed to know and trust their healthcare professional, clinicians needed to feel they could trust patients to deal with acute situations:

"Yeah, I mean the aim's the same, you know, to give patients support and give them education, training and to give them an individual who they can identify with and to try and, as we say, keep them at home and to try and reduce length of stay which in community hospitals is considerable." [Rural PCO: Respiratory consultant]

"We do know an awful lot of patients and it's not just knowing their health problems it's knowing their lives quite often because patients with chronic disease it's not always their health that is impacting upon their need for you at that time, it might be housing, social, emotional, all those sorts of things and we do build up, you know, quite long term relationships with these people." [Merged PCO: Specialist respiratory nurse]

"I have asthmatics, I have COPD patients who have steroids at home or have antibiotics and are happy with that. They're a selected group, it's not everybody, it's the people I trust who have been through it before where most, more commonly than not they're saying 'If only I had this by my bedside I could have avoided a hospital admission or this would not have gone on so long'." [Rural PCO: GP]

Flexibility of service provision was highlighted, both to enable regular reviews (a recognised challenge in asthma care) which could help sustain a personal relationship, and also to allow timely access to acute advice from the professional with whom there was an established relationship:

"We're a very small practice and we just find that if you can be…the more flexible you can be, the more likely they are to come in." [Rural PCO: Group of primary care nurses]

"The nurses share the respiratory and there isn't one nurse who's taken on board the respiratory…and maybe that's something we should think

about because part of the follow-up is about the nurse knowing the patients. It's knowing how to chase them up, it's knowing what their needs are, out of the education and out of the clinics." [Rural PCO: GP]

"It has made a huge difference to them, you know, sometimes just through very simple measures, writing up repeat prescriptions properly or, you know, having just a proper self care plan that they understand and having someone they can phone up and say 'Yes, you should [start] steroids'." [Commissioning PCO: GP]

9.3 Conclusions

The health professionals we interviewed in phase 1 and 2 of our study had various ways of thinking about and different methods of encouraging patient involvement. Generally interviewees acknowledged the need for patients' views to be heard and adequately addressed, however several highlighted the difficulties in ensuring that patients' experiences, needs and thoughts on their care are included in planning and designing services.

Professionals endorsed the importance of promoting self-care and many discussed actively encouraging patients to become partners in care, and thus take responsibility over the management of their care needs. In highlighting the importance of establishing good patient/provider relationships, developing trust and ensuring flexible access to care when needed, professionals echoed those views of the patients.

10 Discussion and conclusions

This chapter summarises the findings from the three phases of the study, outlines the strengths and limitations, discusses the findings in relation to our objectives and finally draws conclusions.

10.1 Summary of the overall findings

10.1.1   Phase I: screening interviews

Against a backdrop of uncertainty due to the impending reorganisation and, in some cases, large financial deficits, the PCOs in our study sought to marshal their resources to develop new services to meet the increasing needs of a population with long-term respiratory conditions, in accordance with the central policy to shift care for people with LTCs cost-effectively into the community. However, the design and implementation of new services were subject to a broad range of local, and at time serendipitous influences which could, and often did, derail the process. Some interviewees described teams of clinicians and managers able to balance policy requirements and local needs in order to develop innovative care, albeit limited by financial restrictions and often with an uncertain future. Most, however, highlighted the many barriers to progress, describing initiatives suddenly shelved for lack of money, progress impeded by reluctant clinicians, plans for reducing hospital care thwarted by 'Payment by Results' and a PCO workforce demoralised by the upheaval and job insecurity of a merger. For many of our interviewees, there was a large gap between policy rhetoric and practical reality.

The services currently being developed by PCOs were aimed at reducing COPD admissions and were therefore focused on the care of people with high-risk, complex needs. Despite universal awareness of the LTC pyramid, only a minority of the PCOs had a coherent strategy to ensure that all patients with respiratory disease had access to a high quality service. The specialist services, most commonly nurse-led intermediate care, had a limited remit to provide education for primary care and few were actively involved in the strategic planning of services.

PCOs commonly turned to the hospital trust for expert advice on developing 'hospital at home' services, but active involvement of clinicians from both primary and secondary care was less common. We identified an association in our data between, on the one hand, collaborations involving primary and secondary care clinicians and PCO managers and, on the other, the provision of specialist services with a broad remit of service development. This involved not only providing clinical services for patients with more complex and severe disease, but also strategic and educational roles which aimed to improve general practice and community standards of care. Where successful teamwork was achieved it was valued and seemed to result in a fruitful alignment of objectives, whilst in other PCOs, the

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challenge of overcoming lack of interest, antagonism, and entrenched attitudes could appear to be insurmountable. PBC was seen as a potential enabler of clinical involvement.

10.1.2   Phase II: case studies

The planning process in all case study settings was diffuse, serendipitous and often interrupted by financial circumstances, local policy and/or changes in personnel. The study was carried out in the early phases of the reorganisation of NHS England into larger PCOs with a stronger commissioning function, and devolution of commissioning to local clinicians through PBC. The destabilising effects of the reorganisation on service planning in this phase were apparent.

The upheaval associated with the reorganisation weakened the commissioning structures as a mechanism for strategic service planning towards cohesive service systems addressing local needs. Planning veered towards short-term considerations (for example: reductions in referral to acute care) at the expense of longer-term system change to provide care and support for patients with different levels of need and complexities of condition. The emerging policy of contestability introduced a range of competing providers from the private and NHS sectors, adding to the complexities of service planning and creating divisions among key players in the planning process.

Against this background, a main factor shaping service reconfiguration was negotiation and contest of professional territories among clinicians moving into new specialist roles in the 'intermediate' sector opening up between secondary and primary care. The co-operation of consultants and hospital trusts was key to service development across the secondary-primary care interface. This was facilitated where there were local opportunities and incentives for secondary care providers to expand (super) specialist services and move away from the contest for intermediate care territory. The formation of service planning teams, encompassing primary care, PCO and secondary care clinical and managerial interests could enable negotiations and allow an alignment of interests that could underpin strategic planning.

There was some evidence that the formalisation of the commissioning process in 2006 and increased competition among providers, together with the upheavals following reorganisation, had an adverse effect on the conditions for development and consolidation of relationships and effective networks which hitherto had allowed a longer-term strategic approach to service and workforce reconfiguration.

Personal contacts and networks which provided access to people, committees and organisations where key decisions were made about resource allocation for service development, were an important resource for clinicians moving into new roles in the 'intermediate sector'. GPwSIs' personal networks provided access to these sites. Their relationships to managers who could argue 'the business case' to PCO players, and their relationships to PBC groups and leads, put them in a position to shape decisions and lead developments. The GPwSIs also had access to a national

network providing information, contacts and support, and lobbying for GP interests. By comparison, nurses' access to decision-making groups was limited, and their support networks were informal. They, therefore, had fewer opportunities to shape their roles and the service developments of which they were a part.

10.1.3   GPwSIs: their role, training and accreditation

The GPwSIs in our screening interviews and case study PCOs undertook clinical, strategic and educational roles within their PCOs. They were all involved in the strategic reconfiguration of local services, some leading service development and sometimes acting as champions. Most had a clinical role, though often leading a clinical team and not necessarily personally providing a clinical service. The majority had an educational remit, providing informal teaching for members of the respiratory team, and also raising standards amongst their colleagues, where their status as an acceptable source of advice and education for GPs was valued.

Training, both experience-based and diploma-based study, followed by formal accreditation were seen as important (albeit challenging and time consuming), both to satisfy governance requirements and also to develop the career of and provide specialist credibility for the GPwSI. Mentoring with a secondary care consultant was valued not only to complement formal study but also to build relationships between primary and secondary care.

GPwSIs (and other clinicians operating in similar roles) have important training needs beyond those of their clinical speciality if they are to undertake the strategic roles within service development.

10.1.4   Phase III: Patient perspective

The patients were acutely aware of changes that affected their experience of personal care provision and picked up on issues surrounding professional response to and co-ordination of their care needs, changes in the availability and type of providers and the impact on their relationships with clinicians. Several patients experienced their care as fragmented and found the increasingly complex systems difficult to navigate, describing difficulties in accessing new services. Identification of, and access to providers in the community (most commonly specialist respiratory nurses and community matrons), who were described as fulfilling a co-ordinating and supportive role, was often a matter of chance. In addition, patients showed awareness of and interest in what was happening at regional and national levels, often explaining changes and developments in the light of financial cutbacks in the NHS.

Patients were aware that professionals are increasingly promoting patient involvement in their own care and self-management. All the patients we interviewed engaged in self-care in one way or another for different reasons and had various sources of support upon which they relied, carers often being a very important aspect of self-management. While several patients were content with the trend towards self-care, at times others felt

abandoned by their professionals and expressed the need for occasional contact, not only for monitoring and medical check-ups but also for the reassurance and support that they saw as underpinning a caring relationship. The desire for flexible access (timely, and employing a selection of face-to-face, telephone and e-mail communication) to professional support emerged as fundamental in ensuring confidence with managing the disease. Patients were also involved in a process of securing relationships and open communication with professionals, a process which was influenced and shaped by various factors, including patient characteristics and clinicians' behaviour and responses. Our data also demonstrate that patients were involved in decisions about their care and treatment patterns, indicating a stage beyond self-care into negotiations which could shape professional care.

10.1.5 Professionals' perspectives on patient involvement

Generally professional interviewees acknowledged the need for patients' views to be heard and adequately addressed, and indeed welcomed the possibility. However several highlighted difficulties in ensuring that patients' experiences, needs and thoughts on their care were included in planning and designing services. Professionals echoed patients' emphasis on the importance of establishing good patient/health professional relationships and ensuring flexible access to care when needed in order to support self-care.

10.2 Limitations and Strengths

Screening interviews

Our 30 screening interviews may not have encompassed the broad range of contexts in PCOs in England and Wales. However, we purposefully sampled trusts with a wide geographic and demographic spread and a range of proposed respiratory service models. We continued to recruit until saturation was reached. Our data are derived from a single interview in each PCO, and although we standardised our requests to PCOs, asking to speak to the person responsible for driving the reconfiguration of respiratory services, some interviewees may not have been fully conversant with the situation in their organisation. The interviewees had a range of clinical and/or managerial roles, and we recognise that their answers and perceptions will have reflected their individual perspectives. Interviewees may have omitted to mention some issues, though we used a structured topic guide to ensure that we asked specifically about relevant issues. The idea that there might be an association between clinician – manager collaboration and breadth of service provision emerged during the analysis, so although our topic guide covered all the relevant issues, we did not systematically request information about this relationship.

Case study selection and generalisability

We recruited four case study PCOs, fewer than our original plan of 6 to 8 PCOs which will have limited the range of situations we explored. We approached a fifth case study site, which subsequently decided not to participate. By this time, it was clear that one of our four sites was to merge with four other PCOs two of which had or were considering a GPwSI service. This offered an important opportunity to observe the impact of the merger on service development, and we therefore opted to explore the additional four merging PCOs, effectively providing insight into eight services.

The issue of generalisability in qualitative research is the subject of much ongoing debate in the methodological literature (e.g. (Ferlie, 2001; Ferlie, 2008; Gomm et al, 2000; Silverman, 2000; Stake, 2008)). In relation to case studies, the question arises as to the extent to which broader conclusions can be drawn from them about the wider population: to what extent can the findings from the four PCOs (plus the four additional merging PCOs) in this study be used to derive conclusions about respiratory service reconfiguration in PCOs across England and Wales? It has been suggested that a more helpful concept than that of 'generalisability' (which has statistical connotations) is that of 'applicability' or 'transferability' (Guba, 1981; Lincoln and Guba, 1985). Underpinning 'applicability' or 'transferability' is the concept that *"although direct comparability between settings is impossible, some similarities do exist between different settings and it is possible to develop working hypotheses which have some potential for transfer between different settings"* (Murphy et al, 1998). The researcher is aiming not at statistical generalisation but at conceptual generalisation: interpreting a particular set of results in the light of some broader theory (Coffey and Atkinson, 1996; Gomm et al, 2000; Green and Britten, 1998; Yin, 2003).

For such 'extrapolation' to be possible, two requirements must be met. The first is careful initial selection of cases (Murphy, 2001; Silverman, 2000). In this study, as described in Chapter 3, we used a theoretically-based framework to select participant cases drawing on the dimensions suggested by earlier work and the themes emerging from the screening interviews. The second requirement is that the researcher provides a full description of the original setting to enable the reader to extrapolate (or not) from selected cases to their own situation (Geertz, 1973; Mays and Pope, 1999; Murphy, 2001). The presentation of the case study findings in Chapter 6, therefore includes a detailed description of the circumstances and events in each case study PCO.

This argument applies not only to 'transferability' to other PCOs, but also to applicability of our findings and recommendations to service development and workforce reconfiguration for other LTCs.

Interviewees and context

Within the constraints of the study we could not interview all possible informants or follow up all possible issues presented. However we ensured

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that we explored all key issues from the perspectives of PCO managers operating at different levels of the organisations, and of primary and secondary care clinicians, including representatives of medical and nursing professions. Interviewees may have been cautious in the information they provided, but seeking interviews with a range of informants in each PCO on several occasions over the year, enabled us to develop relationships and explore sensitive issues.

The national workshop to which each case study was invited to send at least one representative offered an opportunity for stakeholders to discuss our accounts of their stories and check their accuracy. Three of the four PCOs were able to attend.

We carried out our study in the early stages of a major NHS reorganisation in England and Wales, when the immediate upheavals following in its wake had a marked impact on service developments. The services that we observed were not stable and new initiatives, such as PBC, new policies and changes in personnel will impact on future developments. Although our study lasted for a year, events will continue to evolve, and we cannot claim to have seen any of the stories through to a conclusion. In particular, during the time of the study, the new commissioning structures, particularly PBC, were embryonic and although we witnessed the initial impact of the new policies we are unable to comment on their longer-term effects.

Phase III: Patient perspective

Despite using similar methodology, recruitment was not evenly distributed across the case study PCOs, as response to our invitations and advertisements differed. For geographical reasons recruitment in Rural PCO was particularly difficult, and it became clear that it was not realistic to undertake a focus group in such a remote area. This may have limited the opinions gleaned from this PCO, though the interview data did not suggest opinions differed substantially from those in other areas.

We recognise that people who volunteer to participate in research are self selected and likely to be those with particular interest in the topic. Our participants may not, therefore, have encompassed the full range of the views on healthcare services and care of respiratory disease. This problem is exacerbated when using impersonal 'advertising' techniques which inevitably have a low response rate. However, we believe that our broad sampling strategy was more representative than if we had limited recruitment to personal invitations to the small minority of patients who had had contact with a GPwSI, or other specialist service. In addition, we reached data saturation and no new themes emerged during the final interviews or focus groups.

The issue of 'transferability' of findings from a limited number of PCOs and one disease area is discussed above. In the context of the patient interviews we observed no difference in the opinions from each of the case study areas, lending confidence to their wider extrapolation. No younger adults contacted us, so our data may not be representative of the views of younger people.

In addition, due to the need to focus on the specific objectives of the study, we may have missed some elements which participants deemed important in relation to dealing with their condition. However, the illness diary provided an opportunity for patients to record whatever they wished so that any important unexpected themes should have emerged. Their interesting and generous narratives and accounts gave us an even broader context within which to place our findings.

The combination of methods we used allowed insights into managing a chronic condition over a period of time and provided the opportunity for patients to voice their internal reflections in the illness diaries. This element, along with the serial phone calls between the study participants and the researchers, allowed a trusted participant-researcher relationship to develop within which experiences could be related.

Multidisciplinary expertise

A major strength of the study is the multidisciplinary expertise (clinical, health service management, anthropological) available within the study team, ensuring balanced conclusions.

Some of the team are involved with the GPIAG, an organisation which, in keeping with its key aim of optimising respiratory care, is promoting a number of developments relevant to this study. In particular, it is actively encouraging PCOs to focus on the needs of people with respiratory conditions and is promoting the potential of GPs (and nurses) with Special Interests to achieve this aim. This connection had advantages in facilitating access to appropriate stakeholders but we were aware of the potential for introducing bias. However, the involvement as co-applicants and collaborators of people unconnected with the GPIAG ensured a balanced and nuanced view. The interchange between 'insider' and 'outsider' perspectives on service development proved productive for analysis and interpretation of data and has, we believe, resulted in a rich description of service development, aiding transferability and utility of findings (Geertz, 1973).

10.3   Discussion in relation to objectives

10.3.1   Objective 1. To identify key drivers of respiratory service reconfiguration in a sample of PCOs

Central policy and local need

The two key policies, which drove the reconfiguration of respiratory services, were the need to address the increasing needs of people with LTCs (Department of Health, 2004c; Department of Health, 2005c; World Health Organisation, 2002), and the imperative to deliver care closer to home (Department of Health, 2000b; Department of Health, 2004f; Department of Health, 2005b; Department of Health, 2006a; Department of Health, 2007c). Recognition of the significant impact of respiratory disease on hospital bed days (British Thoracic Society, 2006; Damiani and Dixon, 2002; Damiani and Dixon, 2004) has focused the attention of PCO

managers on the management of people with COPD. The national COPD guidelines (National Institute for Clinical Excellence, 2004) and the reports that presaged the announcement of an NSF for COPD (Commission for Healthcare Audit and Inspection, 2006; Department of Health, 2004d) have further encouraged interest in respiratory disease, though our interviewees generally saw the NSF as a challenge for the future rather than an immediate one.

The LTC pyramid of care was almost universally cited as a framework for developing services for people with LTCs (Department of Health, 2004c). However, almost all the developments described by our interviewees addressed the needs of patients towards the top of the pyramid, and focused predominantly on reducing admissions. This narrow focus overlooks the importance of ensuring early diagnosis and strengthening disease management and supported self-care for those at lower levels of the pyramid to prevent progression and future escalation of care needs (Commission for Healthcare Audit and Inspection, 2006; Department of Health, 2005c; National Institute for Clinical Excellence, 2004). Unless the focus on admission prevention is underpinned by predictive models which can accurately identify 'at risk' patients (Curry et al, 2005), this approach perpetuates some of the limitations of the reactive approach to acute care.

Financial considerations

Financial considerations and the need to address overspend in budgets were another driver of service development (Department of Health, 2006b) which could result in short-term planning (often no further than the end of the current financial year) and a focus on single services for immediate cost savings from reduction in acute admissions at the expense of longer-term strategic capacity building in the service system as a whole.

Models and functions of the services

The nurse-led services (delivered by specialist respiratory nurses, community matrons or both) described by our interviewees were in line with policy which promotes the role of nurses in providing care for people with LTCs (Department of Health, 2002b; Department of Health, 2005d; National Workforce Projects, 2006). Almost all had the primary remit to reduce admissions, though some were developing, or hoping to develop, other services such as pulmonary rehabilitation which were evidence-based (National Institute for Clinical Excellence, 2004), though less a priority for funding, as they were not explicitly linked to policy imperatives. Some PCOs specifically mentioned other relevant, though separate, initiatives such as smoking cessation services and Expert Patient programmes (Department of Health, 2001b).

PCOs were aware of the need to raise the standard of respiratory care within primary care, both within general practice and community nursing teams, though this role was often squeezed out when resources were scarce. GPwSIs were particularly valued as being able to influence medical colleagues who were not always receptive to training delivered by specialist respiratory nurses.

New roles

Whilst normally considered a result of reconfiguration of services, the emergence of new roles may also be a driver of change. Our data support the potential of experienced management and 'credible local champions' to impact on service development (Moffat et al, 2006). GPs with long-standing clinical interests and primary care professional organisations have embraced the role of the GPwSI and have been responsible for discussing and extending the concept (Dhumale, 2004; Galloway et al, 2002; General Practice Airways Group and Royal College of General Practitioners, 2003; Gerada et al, 2002; Jones and Stevens, 2001; Rosen et al, 2003; Williams et al, 2002), actively promoting the model as a means of improving care (General Practice Airways Group, 2005; Hay and Adebajo, 2005; Rogers, 2002), and encouraging research to further an understanding of the role (Gilbert et al, 2005; Kernick, 2005; Moffat et al, 2006; Pinnock et al, 2005). Amongst our interviewees we saw examples of 'interested GPs' approaching PCOs and championing the development of a model of respiratory care including a role for a GPwSI. There was also an example of a consultant approaching the PCO to establish a community respiratory physician post for his specialist registrar. Our findings would suggest that, whilst not conforming to the ideals of transparent commissioning (Department of Health, 2007e), PCOs, more used to being faced with lack of interest from clinicians, were glad to make full use of such expertise. An additional benefit of the GPwSI role is as professional development for GPs (Department of Health, 2000b; Department of Health, 2002a; Gerada et al, 2002), and we identified two PCOs who had used GPwSI training to overcome recruitment problems in their area.

10.3.2 Objective 2: To identify the factors (including local context, knowledge/evidence base, available resources and perceptions of clinical roles) which shape the planning and implementation of workforce change

'Mind the gap'

Our data identify a significant gap between aims and desires at policy level, and how services are designed and implemented at ground level. Whilst policies were described as significant drivers of change, our interviewees discussed many other important factors impacting on practical service reconfiguration. Echoing the diversity which has already been reported at Strategic Health Authority level (Singh and Ham, 2006), the manner and success with which PCOs translated the aspirations of policy into reality were very variable. As a result, services can look very different to users in different PCOs, potentially raising concerns about inequity.

The local context was important, with factors such as availability of managers and clinicians with an interest in respiratory care, service histories, budget constraints and opportunities, and perceived patient needs, identified as impacting on service developments. Issues which

emerged from our data as impacting on reconfiguration of workforce and services were:

- the impact of change,

- the formalisation of commissioning structures and processes,

- the negotiation and contest of professional boundaries.

The impact of change

The study took place during a period of major reorganisation of NHS England and Wales (Department of Health, 2005a). The reorganisation offered a range of new opportunities for workforce reconfiguration, for example through the merger of PCOs into larger units with opportunities for service expansion and roll out. However, the changes also had a substantial and often distracting effect on managers and clinicians, who were preoccupied with reorganisation and job losses in their own and neighbouring organisations, and were unable to look beyond services in the short-term because of the high degree of uncertainty about the future context (Cortvriend, 2004; Fitzgerald et al, 2006; Fulop et al, 2002). Addressing budget deficits, some of which were increased as a consequence of mergers, was an important, and at times over-riding, priority.

The formalisation of commissioning

The reorganisation in October 2006 introduced a strengthening and formalisation of commissioning structures and procedures, with a clearer division between PCO commissioners and hospital trusts and an increased number of providers of services as a means of increasing competition (Department of Health, 2005a; Department of Health, 2006b). During the time of the study, these new structures, particularly PBC, were embryonic and we were able to observe their initial impact.

With the increasing emphasis on formalising service arrangements through audit, contracts based on cost and outcome and performance management, informal arrangements were increasingly difficult to sustain. Whilst this made service development more structured and transparent, the rigorous performance management according to contract specification made extension of provision more difficult because time and workforce resource could be used less flexibly. It was harder to find the time to establish networks and maintain relationships upon which successful and sustainable arrangements rested.

In the short-term, the embryonic new commissioning arrangements could disrupt relationships and structures, including existing commissioning arrangements, which underpinned current workforce developments. The new commissioning arrangements also increased tensions between PCOs, hospital trusts and primary care clinicians. The linked policy of contestability opening the English healthcare market up to new (private) providers, further increased competition and tension.

The fragmented and immature commissioning structures, combined with the priority to address budget deficits in the short term, generally limited

service development and workforce change to isolated service provision for patients with severe and complex disease where there was potential to make savings on hospital costs within the financial year. This stalling on broader service redesign was predicted in commentaries on the impact of the 2006/7 operating framework (The King's Fund, 2006).

The negotiation and contest of professional boundaries

Negotiation and contest among clinicians in new specialist roles in the 'intermediate' sector was a key factor in service reconfiguration, particularly between secondary and primary care medical professionals. If proposed service arrangements were perceived to threaten existing secondary care professional interests and to provide no compensating factors (such as the opportunity to expand into new specialist areas), they were strongly resisted. There was some evidence that PCO commissioning and PbR encouraged secondary care providers to move away from service development in the 'intermediate' sector, where they competed with primary care-based specialist services, and to concentrate on developing services in the hospital sector.

In the volatile environment created by short-term effects of reorganisation, players fell back on personal relationships and networks based on collegiality and common professional interest to push developments through or keep arrangements going. Personal relationships among clinicians could, up to a point, offset disruptions to services caused by reorganisation. Personal networks and relationships were also important in development of services. GPwSIs' access to networks which linked them to seats of key decision-making regarding deployment of resources, for example PBC Groups and PCO commissioning fora, was a key resource which could enable these professionals to shape and lead workforce reconfiguration. The potential of GPwSIs to act as local leaders was predicted in early discussions (Williams et al, 2002) is now formally acknowledged (Department of Health, 2002a; Department of Health, 2007a) and is emerging as an important function. By contrast, specialist nurses' networks were more informal and remote from seats of important decision-making, thus affording less opportunity to shape developments.

Teamwork

Integrating care across primary and secondary care, and enabling collaboration between multidisciplinary teams of healthcare professionals are enshrined in policy (Department of Health, 2004f; Department of Health, 2005c; Department of Health, 2006a), widely advocated in discussion (Black, 2006; Commission for Healthcare Audit and Inspection, 2006; Fulop et al, 2007; Irani et al, 2007; Light and Dixon, 2004; National Institute for Health Research, 2000; Wagner, 2000), and supported by evidence (Battersby and SA HealthPlus Team, 2005; Department of Health, 2007d). The few PCOs in our study with multidisciplinary teams in place integrated between the hospital sector and the community seemed better placed to address all levels of the LTC pyramid with their planned respiratory services, providing some support for the fundamental

importance of multidisciplinary co-ordination of care in realising the potential for improved patient care (Battersby and SA HealthPlus Team, 2005).

These multidisciplinary teams could mitigate some of the adverse effects of professional contest and of the turmoil arising from organisational change. However they were dependent on a range of factors: luck, local personalities and resources to support the team such as training, time and access to centres of decision-making. There was some evidence that, compared to the more informal commissioning arrangements of the period before the 2006 reform, the formalisation of commissioning procedures, combined with the instability of commissioning structures and upheavals and tensions following the reorganisation, afforded less opportunity for teams to form, align perspectives, negotiate a joint vision and consolidate strategy.

10.3.3   Objective 3. To understand the infrastructure, support and training required successfully to achieve appropriate workforce change in delivering respiratory care

Functions of a specialist service and training needs

Gask argues that a specialist (a consultant physician in the US managed care organisations on which she bases her argument) should not only address the clinical needs of those with severe or complex illness, but also has a responsibility to *"improve the quality of care for those who don't need specialist care"* (Gask, 2005). The evolution of the GPwSI concept reflects this broadening of emphasis as the initial description of a GP undertaking a specific clinical task (Department of Health, 2000b) has been challenged in subsequent discussions (Williams et al, 2002), and official guidance now recognises the potential contribution GPwSIs can make to strategic development of services, and raising standards in primary care (Department of Health, 2003a; Department of Health, 2007a). Previous surveys and qualitative work have endorsed this broader remit for GPwSIs (Boggis and Cornford, 2007; Moffat et al, 2006; Pinnock et al, 2005). Our findings suggest that, at least in some PCOs, these roles may be incorporated into the design of a specialist service, with different professionals fulfilling clinical, educational and strategic roles to ensure a comprehensive service. Furthermore, the strategic and educational roles were central to the remit of the GPwSI services in the PCOs we sampled, sometimes prioritised above the personal provision of a clinical service. This contrasts with the formal accreditation framework which focuses exclusively on ensuring safe clinical practice within GPwSI services (Department of Health, 2007a).

The GPwSIs in our study all agreed that, in addition to specialist clinical training, there was a need to develop management, leadership skills and an understanding of the commissioning process in order to enable them to fulfil a strategic role. Mentorship was highly valued, not only as a means of

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developing clinical skills but because of the opportunity to work across the primary-secondary interface.

As early pioneers, our informants were unlikely to illustrate typical future training needs if the GPwSI role becomes more mainstream rather than the ambition of a few. Four of the six GPwSIs we interviewed were existing 'champions' of primary care respiratory medicine and were accredited by submitting a portfolio of their previous experience. (Gruffydd-Jones K, 2005) Only two had undertaken a formal training: one had a long-standing interest in respiratory disease before being invited to develop a GPwSI role, the other was a young GP attracted to an under-doctored area by an educational programme. These programmes required considerable commitment (two days a week for a year, or one day a week over 18 months) on the part of both the GPwSI and the funding PCO.

Support

In addition to practical support needs (struggles obtaining access to hospital notes were a basic example of where this support could fail) the GPwSIs' services were normally supported by a multidisciplinary team including specialist nurses, physiotherapists and healthcare assistants. A health economic evaluation, much cited by our informants, concluded that a GPwSI clinic was more expensive than a consultant service, mainly because the GPwSI personally saw the patient on each occasion whilst the consultant clinics employed a range of staff grades (Coast et al, 2005). The GPwSIs in our study, however, were able to delegate to members of the team, potentially reducing costs.

10.3.4 Objective 4. To examine the relationship between changes in respiratory services and patient experience when respiratory services are reconfigured

Workforce changes

Patients appreciated the 'human' aspects of new workforce roles and teams which were described as accessible (*"in the neighbourhood"*), offering the possibility of building stronger relationships, and able to take account of patients' everyday needs. Many of these new roles and teams were mentioned in the context of co-ordinating care with social and mental health services on their patients' behalf, thus providing continuity of care, an aspect increasingly acknowledged as promoting a more patient-centred model of care in previous research (Baker et al, 2006; Gulliford et al, 2006; Gulliford et al, 2007; Woodward et al, 2004) and now enshrined in policy (Department of Health, 2004c; Department of Health, 2005c; Department of Health, 2005e; Department of Health, 2006a).

Many responses illustrated patients' awareness and expectations of knowledge hierarchies amongst professionals and demonstrate their distrust towards new roles that may compromise the quality of their care. New nursing roles in the community caused some confusion and speculation as to their expertise vis-à-vis the doctors. Some patients were impressed by

the 'specialist' training of some of the new nursing roles, whilst others were unsure about their authority and expressed discontent with what they felt were additional barriers to accessing the 'real doctors' at the hospital. While the GPwSI role might be considered differently in the hierarchy of roles and authority on medical knowledge, too few patients had consulted with one for us to make a representative statement. These findings echo those of previous qualitative work on the role of GPwSIs which identified the value patients place on expertise (Coast et al, 2006) and similarly questioned whether generalists could really be specialists (Moffat et al, 2006).

Fragmentation of care

Patients were very aware of the increasing number of professionals, specifically the various nurse roles and specialist services and expressed confusion with their navigation through the disease experience. Those who did not have access to a central figure, (such as a community matron, or respiratory nurse) often mentioned their need for a professional who could *"tie things together"* especially as the traditional role of the family doctor was perceived as waning. This was particularly evident when patients perceived they were being passed between providers who were not communicating with each other, and when their co-morbidity necessitated attendance at a succession of specialist clinics. GPwSIs, trained and accredited to work in a specific specialist clinic, risk further fragmenting care unless the current emphasis on a generalist background continues to be prioritised (Department of Health, 2002a; Department of Health, 2003a; Department of Health, 2007a; Gerada et al, 2002; Royal College of General Practitioners, 2001; Royal College of General Practitioners and Royal College of Physicians of London, 2001).

New service developments

The overall sense of haphazardness in finding out about new services suggests a need for better dissemination of information about what is available locally. Despite the fact that some patients mentioned support groups as a good source of information on local developments, few attended the groups and many did not know where to find out about support. Although clinicians were suggested as a possible source of information, several patients had the sense that clinicians were not aware of local developments either and suggested that there was a need for user-friendly advertisement of new services to both patients and professionals. More active management of referrals, including audit and feedback of current practice, has enabled successful implementation of a number of GPwSI clinics in one PCO (Hill and Rutter, 2001).

Awareness of system changes

Patients demonstrated their awareness of changes at national level and showed great interest in the causes behind those changes. Many interpreted their personal experiences in the light of national developments which they followed through various sources of information, including the

media, their social networks and support groups in which the informal atmosphere often allowed more open discussion outside of the purely medical domain. Despite the considerable levels of interest in the forces that impacted on the health services, the structures and systems driving the changes were somewhat opaque and strengthened the general assumption that financial motives were the main, if not only, force behind any new developments (Collins and Grazin, 2008; Kirkip, 2008).

Patient involvement at strategic levels

Policy on patient and public involvement intends that patients should be involved at all levels, including in the design and planning of services at local and national levels (Department of Health, 2004f; Department of Health, 2006a). The literature makes clear that this may not be straightforward: patients differ in the extent to which they wish to be, or are able to be, involved at higher levels of service design (Gagliardi et al, 2008; Litva et al, 2002; National Institute for Health Research, 2000; Thompson, 2004) and a range of strategies are needed to address the attitudinal and structural barriers to such involvement (Crawford et al, 2004; Kennedy et al, 2007; National Institute for Health Research, 2000; Thompson, 2004).

Echoing the situation nationally (Audit Commission, 2004; Department of Health, 2007b) patient representation and involvement in the model development phase was very limited in the PCOs we interviewed. It was rare for a patient to be formally involved as a member of the local team responsible for designing services, although many of the PCOs acknowledged the importance of designing services around the needs of the patient, (Department of Health, 2004f) and some invested significant resources in actively seeking feedback from users of the respiratory services to feed into the process. Local patient pathways were seen as important development tools to facilitate patient-centred care.

We found that although some participants were involved in local activities (e.g. talking in schools about respiratory conditions), none of the patients we interviewed were currently involved or expressed intentions of getting involved at the planning and programme levels of the health system. However, in the light of their awareness and strong interest in the changes around them, there appears to be considerable scope for increasing patients' involvement in service design at these levels.

10.3.5 Objective 5. To examine patients' awareness and perception of workforce changes in the context of overall management of their respiratory disease

The participants in our study were aware of the shift towards self-care in the overall management of their respiratory disease, and discussed a number of aspects of the boundary between self- and professional-care.

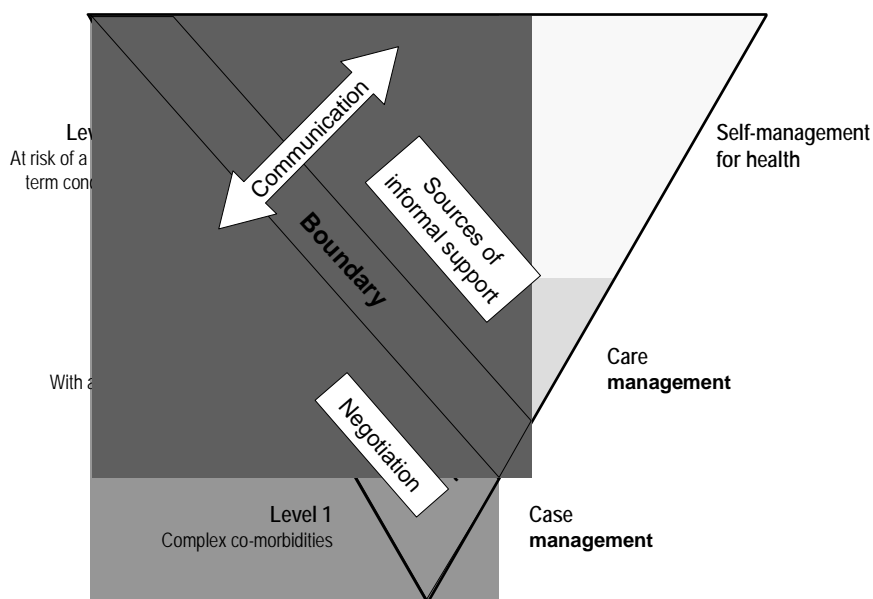### Self-care and the need for healthcare professional support

Our findings support research that argues that patients vary in the desired extent of their involvement in self-care and that their relationship with professionals is one of the key determinants (Thompson, 2007). The patients in our study were more confident when they experienced regular contact and good communication with their clinicians, resonating with evidence and guideline recommendations on 'guided self-management' in asthma (British Thoracic Society and Scottish Intercollegiate Guideline Network, 2003; Gibson et al, 2002; The Global Initiative on Asthma, 2007). While some studies argue that effective self-management is achieved when efforts and support are focused around the patient in their education and behavioural modification (Bourbeau et al, 2004; Van Dam et al, 2003), our findings support other research that argues that patients perceive external barriers to effective self-management including poor communication with providers. In this sense, professionals' communication skills and ability to respond appropriately, not only to patients' medical care needs, but also to their need for support and knowledge, surfaced as an important aspect of enabling self-care. In agreement with (Coulter and Ellins, 2007) we would emphasise that patient self-care supplements rather than replaces interactions between patients and professionals.

Complexity of self-care

Our findings demonstrate the considerable complexity of self-care and associated support needs and the importance of not categorising patients into those who actively manage their condition and those who do not, those who need more professional input and those who do not. In fact, patients take on different roles and have different needs throughout the experience of their illness, sometimes becoming more involved in their care, sometimes less, depending on various factors, including the level of desired involvement and type of communication they have with their clinicians.

In order to illustrate the fluidity of patients' needs for access and communication with professionals in the process of self-management we propose (Figure 7) a modified version of Degeling's model of support for patients with LTCs (Degeling et al, 2006a). This includes the three service modalities proposed in Degeling's model (self-management for health, care management, and case management) but additionally outlines three 'realms' (self-care, boundary and professional care) within which patients take on different roles and access different types of support.

Figure 7. The chronic disease management pyramid with the boundary between professional and self-care (adapted from (Degeling et al, 2006a)

(Figure contains the following labels: Communication; Boundary; Sources of informal support; Negotiation; Self-management for health; Care management; Case management; Level ... At risk of a ... term cond...; With a...; Level 1 Complex co-morbidities)

The 'realm' of self-care

Our findings indicate that many patients, especially when experiencing less severe symptoms, are relatively comfortable in the 'realm' of self-care by relying on their own knowledge of the condition and/or accessing support from alternative sources, such as complementary therapists, information from the internet and their friends and relatives. Comfort is enhanced when patients feel confident that they could access providers promptly for advice or guidance if and when they feel it is necessary. In addition, occasional and flexible contact via phone, email or brief visits initiated by their clinician could add to feeling *"cared for"* thus avoiding situations in which patients in the self-care realm felt *"abandoned"* by professional care.

The boundary between self-care and professional care

While Degeling (Degeling et al, 2006a) characterises the area connecting patients and professionals as 'support', we suggest that it may be better described as a boundary area, into which both sides dip in various ways (e.g. written, telephone communication or face-to-face consultations and visits) and which can be easy, or difficult to cross. Our findings show that communication and relationships are key in determining the flexibility and desired frequency of contact between both sides. Patients seemed to be more content to self-care when their relationships with clinicians were based on trust, confidence, familiarity, mutual respect and good communication, resonating with those studies which emphasise the importance of professionals' responses and reactions to patients in facilitating communication and effective exchange of knowledge (Entwistle et al, 2008; Wilson et al, 2006). In common with the study by Charles and colleagues on decision-making in the physician-patient encounter (Charles et al, 1999),

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our findings underline the fluidity of patients' roles, fluctuating between more passive or active mode dependent on various factors including their perceived ability to communication with their clinician, the perceived levels of trust and confidence in the expertise of the clinician.

Stepping beyond the boundary: Negotiating professional care

Our findings also demonstrate that some patients will go a step further and become involved on the professional management side of the 'boundary' as they negotiate their care and make decisions on their treatment and medication intake. For example, several patients described their resistance and open confrontations with clinicians, for example when it was suggested they take steroids, as many had heard about and feared the side effects. In addition, patients also showed initiative in negotiating which clinician they saw, especially during an exacerbation. In other contexts, this negotiation may be responsible for the evidence that self-management education and the provision of asthma action plans can attract better treatment (i.e. increased steroid provision) from their attending physicians. (British Thoracic Society and Scottish Intercollegiate Guideline Network, 2003; Department of Health, 2008a; Moudgil et al, 2000; Osman et al, 2002; Thoonen et al, 2003).

10.3.6   Objective 6. Develop guidance on effective models of implementing workforce change to deliver services for people with LTCs

The strategic development of a model of care

In discussing models of care for LTCs, there was broad agreement that the pyramid of care was a helpful framework (Department of Health, 2004c), though the emphasis of each stakeholder group was different. Driven by financial imperatives to reduce hospital admissions (Department of Health, 2004d), and by policy directives to move care closer to home (Department of Health, 2000b; Department of Health, 2004f; Department of Health, 2006a), PCO managers found that they were forced to focus primarily on the needs of the few patients with complex needs. Clinicians tended to bring a broader perspective which encompassed the quality of care *'from cradle to grave'*. Patients focused attention on the need for flexible access across the boundary between professional and self-care and highlighted the dangers of fragmentation of care.

Our conclusion, that effective models of care for people with long-term respiratory disease need to be underpinned by collaborative teamwork and an alignment of these perspectives, echoes the recommendations of a King's Fund report (Dixon et al, 2004) and recent discussion on the process of commissioning care for people with LTCs (Ham C, 2008). A core skill for commissioners will be the ability to engage with all stakeholders, broker negotiations, identify potential leaders and support the development of the necessary skills.

The responsibilities of a specialist service

Our findings resonate with the assertions of Gask (Gask, 2005), that a specialist service should not only provide a clinical service for the more complex patients, but should also contribute to strategic direction and accept responsibility for ensuring the standard of care provided by other health professionals to patients at lower tiers of the pyramid.

Recognition of the contribution of COPD to emergency admissions (British Thoracic Society, 2006; Damiani and Dixon, 2002; Damiani and Dixon, 2004), coupled with financial constraints which encourage a short-term approach to cost savings has resulted in PCOs focusing their resources on the needs of the relatively small proportion of at-risk patients with severe or complex disease.   However, the complexity of confidently predicting those at risk (Curry et al, 2005) and the progressive nature of most respiratory long-term conditions, would imply that attention to disease management and supporting the self-care of those with milder disease may offer longer-term gains (National Institute for Clinical Excellence, 2004).

A *'cradle to grave'* approach to service provision will require a strategic broadening of current provision, including an increased prioritisation of the importance of up-skilling existing primary care and community-based professionals.   Involvement of patients in this process may enable services to recognise, and address the dangers of fragmentation of care that may arise if poorly integrated services are developed along a pathway with insufficient flexibility to respond to the varying needs of patients.

Workforce profile and training

The workforce profile required to fulfil this broad clinical, educational and strategic definition of a specialist service will vary according to the context and human resources in an individual PCO.

With the current emphasis on reducing admissions, an evidence-based nurse-led 'hospital at home' team (Ram et al, 2004), sometimes linked with a policy-driven community matron service (Department of Health, 2005c), was the commonest model described. With a broadening of the remit of specialist services to encompass strategic and educational responsibilities (Gask, 2005) new skills will be needed. The need for training in management skills for specialist clinicians was a common theme for the professionals we interviewed.

In line with the recognised evolution of the role (Department of Health, 2007a; General Practice Airways Group, 2005; Gerada et al, 2002; National Primary Care Development Trust, 2003; Williams et al, 2002), the GPwSIs we interviewed were all engaged in strategic roles within their PCOs. Our data suggest that the relationships and social networks, which linked doctors to groups and fora of decision-making gave them an advantage in influencing strategy and, at times, enabled them to act as 'champions'. By contrast, the specialist nurses we interviewed were not linked into processes of decision-making in the same way. For similar reasons they were also were less confident in their ability to train and influence GPs and other professionals than their GPwSI counterparts.

Our findings highlight the need to include the managerial workforce in plans for training. Commissioners need to be aware of the issues involved in brokering local relationships needed to underpin service development. Service specifications should explicitly address the training and support needs of personnel in new services. Mentoring emerged as particularly important for developing relationships and furthering mutual understanding.

Clinical Networks

Our findings endorse the increasing policy emphasis on enabling collaboration between multidisciplinary teams of healthcare professionals, (Department of Health, 2004f; Department of Health, 2005c; Department of Health, 2006a).

There is a growing call for the development of networks to guide the development of services for people with LTCs. For example, in a report for the NHS Alliance, Irani suggests the formation of Integrated Provider Organisations (Irani, 2008). She envisages that these would enable primary and secondary care clinicians to *'collaborate and lead positive change within the health service through innovation, while ensuring that the local population is truly engaged with preventative healthcare and enjoys the benefits of a flexible, responsive and patient centred health service.'*

Evidence is emerging to support this approach. For example, after nearly a decade's experience of Managed Care Networks in Scotland (Scottish Executive, 2005), the emphasis on engaging both primary and secondary care clinicians is being reinforced (Scottish Executive, 2007). In addition, a clear strategy for involving service users and their carers is defined. There is an explicit need for training for all these stakeholders to enable them to fulfil these new roles. In England, this collaborative approach is endorsed by the recent Darzi report which signals the creation of local *'groups of health and social care staff'* to discuss how best to deliver care (Darzi, 2007).

10.4   Conclusions

The national imperative, interpreted in the light of the local situation (including perceived patient need, financial constraints and workforce availability), to deliver cost-effective care closer to home for people with LTCs, was the key driver of respiratory service reconfiguration

For many PCOs the barriers of financial deficit, organisational uncertainty, disengaged clinicians, and contradictory policies presented insurmountable barriers to the effective development of sustainable services.

Although almost all PCOs were developing services for people with severe disease or complex needs (principally in order to reduce admissions), the presence of multidisciplinary teams integrating primary and secondary care clinicians with PCO management, was associated with broader service provision addressing the needs of patients at all levels of the pyramid.

Models and implementation of workforce reconfiguration are strongly influenced by the presence of clinical and managerial expertise and the

interests of and relationships between local professionals, played out against a broader context of financial deficits and organisational change.

Access to local and national networks of support and influence were important resources for clinicians in new specialist roles. GPwSIs had easier access to such networks than, for example, nurses and were in a better position to influence their roles and remit.

Commissioning focused service planning on the cost-effectiveness of services, but could also destabilise service arrangements by disrupting relationships on which these arrangements rested.

In addition to specialist clinical training, GPwSIs and other professionals in new roles highlighted the need to learn management and leadership skills, specifically to develop an understanding of the commissioning process, in order to enable them to fulfil a strategic role.

Patients were not only aware of changes that affected their experience of personal healthcare, including changes in the availability and type of clinicians, but also showed awareness of (though no active involvement in) what was happening at regional and national level.

Patients generally experienced services as poorly adapted to their needs, fragmented and difficult to navigate without a central co-ordinating professional.

All patients are involved in self-care and many appreciated the ownership of responsibility and sense of control it gave them. However, some were concerned about the limitations of self-care and felt abandoned without professional support.

Patients valued flexible access and regular communication at the boundary between professional and self-care in order to feel comfortable managing their condition

11 Workshop

The positioning of this overview in the report reflects the contribution the workshop made to our study. We presented our data and conclusions to the participants and invited their comment a) to validate or challenge or findings and b) to assist with formulation of the broader implications.

11.1 Summary

These are the key conclusions of the four discussion groups at the workshop broadly related to our objectives.   Guidance on effective models (Objective 6) drew on the findings of all aspects of our study and was informed by discussion in all four groups.

Policy and practice (Objective 1)

Reconfigured services should provide flexible care to meet individual needs and preferences of people at all levels of the LTC pyramid. The three functions of a specialist service (clinical, educational, strategic/leadership) described in the presentations resonated with participants.

To reduce the risk of fragmenting care as the patient moves between services on a care pathway, teams or managed care networks should be responsible for linking existing and new services, and encouraging co-operation (as opposed to competition) across different sectors.

Commissioning and clans (Objective 2)

The NHS is a complex system. Service planning is not a rational/ technical operation, but a complex process driven by a range of often conflicting drivers and factors. It is often a case of 'muddling through', rather than strategic planning.

Opinions were divided as to whether the latest reforms had made the process more structured, transparent and rational. From a service manager/commissioner perspective, this may be the case. From a clinician/provider perspective, the system is not transparent and vital information about rules and principles of commissioning often does not reach providers. The commissioning structures and procedures lack flexibility and risk disrupting local relationships and knowledge upon which effective service delivery depends.

Roles and training (Objective 3)

Private companies tend to invest around 10% of their budgets in staff training and it might be useful if the NHS thought in terms of this percentage and considered investing in cross-NHS training to ensure that the service as a whole had the skills needed.

On-going support and mentoring (e.g. from a consultant) and on-going peer updating are essential in addition to formal training. Participants suggested that a mentor had several roles: educational facilitator; friend/colleague; coach and clinical competence 'backstop'.

Patients and citizens (Objectives 4 and 5)

Patients are a valuable resource and their involvement is imperative to effective and appropriate service design and planning. The current lack of visible impact of patient views on service design is one of the many factors that act as a disincentive to patient involvement.

While self-management is an important aspect of care, it is important to recognise and address the variability of patients and their needs and take into account the importance of flexible and regular access to providers.

11.2 Delegates

The full day workshop was attended by 26 participants. In addition to the core team of co-applicants and researchers, and representatives of three of the four case studies, the attendees included policy makers (including primary care and the COPD NSF team), GPwSIs, consultant physicians, academics, GPs (including a representative of the GPIAG), representatives of patient groups (Asthma UK and British Lung Foundation), commissioners and PCO managers, educationalists, and nursing management.

11.3 Report of break-out group discussions

With data from a briefing document, and following presentations of the emerging themes and conclusions, delegates worked in four multidisciplinary groups to discuss policy, commissioning, training and the patient perspective (see appendix 9 for details of each group's remit). The key points arising from these discussions are summarised below.

11.3.1 Policy and practice

Objective 1. To identify key drivers of respiratory service reconfiguration in a sample of PCOs

Commissioning should move from process to a focus on outcomes, for the majority of people (not just those at the top of the pyramid)

- Current drivers are financial, combined with the policy imperative to reduce pressure on secondary care services: commissioners should be encouraged to focus instead on improving outcomes.

- Outcomes should be evidence-based and patient determined, rather than just focusing on processes that are easily measured, and should set 'markers of good practice'.

- Timescales for achieving outcomes should be realistic.

- Services should address the needs of people at all levels of the pyramid, including those with milder disease where there is potential to prevent progression to a stage where treatment is largely supportive.

Services should be commissioned to provide flexible services to meet the individual needs and preferences of people with LTCs

- A 'toolkit of services' is required (i.e. not just 'clinic-based', but a range of modes of consultation to provide support).

- The roles of GPwSIs, specialist nurses, consultants in the community will vary between PCOs.

- Care for patients at the top of the pyramid will always need co-operation between sectors and professionals (a managed care network may be a good process to enable this). The second tier is largely primary care-based with marked variations in standards that will need to be addressed.

- The third level involves existing services such as smoking cessation and enabling accurate diagnosis.

- PBC is an important opportunity to influence commissioning, but it is too early to tell if it could realise its potential.

- Patient perspectives are very powerful. Addressing the confusion with a plethora of new roles, and ensuring access to expertise and continuity of care are priorities.

Commissioning for LTCs should devise models of care that encourage co-operation (as opposed to competition) across different levels

- It is difficult (but not impossible?) to see how to develop commissioning arrangements which encourage co-operation between providers, and enable delivery of a flexible service encompassing a variety of models.

- Many current models were based on longitudinal care pathways with appropriate services along the way, each with defined standards and outcomes. There is concern that this could fragment care as the patient moves between services on the pathway.

- The involvement of multiple providers, adds the additional concern that they would be competing for the patient, a situation which could further compromise integrated care.

- Services commissioned within the context of a pathway should be overseen by a managed care network to ensure integration of care.

- It is important to recognise that many services already exist. There is a role for managed care networks in linking existing and new services.

- Existing providers need to get themselves 'fit for purpose', or there will be a vacuum into which other providers will come.

Teams and players are important

- GPwSIs will adopt different roles depending on the specialty (e.g reducing outpatient waiting lists in dermatology, increasing provision of endoscopy services). In respiratory services the leadership role (brokering services, designing clinical pathways, auditing standards of care) is important - potentially more so than a direct clinical care role.

- 'Champions' ('ideas persons') are important. The role can move between stakeholders: the key skill is to 'spot the (potential) champion' and enable them to develop.

- There is a powerful message about the importance of teams to provide support and sustainability; ideally these need the involvement of primary and secondary care clinicians and managers.

- Managed care networks perform well where teams work co-operatively, and are built on trust and good relationships.

- Primary and secondary care clinicians are often keen to work together. However there can be deep distrust at management level because of competing (financial) interests.

- There is a need to align perspectives and derive co-linear pathways in order to allow all stakeholders to achieve their goals.

- Commissioning-led business models can 'disrupt' the relationships and benefits of the clinical network (generally made up of providers).

- The competencies of those delivering services need to be addressed. This should include up-skilling practices.

11.3.2 Commissioning and clans

Objective 2: To identify the factors (including local context, knowledge & evidence base, available resources and perceptions of clinical roles) which shape the planning and implementation of workforce change.

NHS is a complex system

- Service planning is not a rational/ technical operation, but a complex process driven by a range of often conflicting drivers and factors. It is often a case of 'muddling through', rather than strategic planning.

- Opinions were divided as to whether the latest reforms had made the process more structured, transparent and rational. From a service manager/commissioner perspective, this is the case. From a clinician/provider perspective, the system is not transparent and vital information about rules and principles of commissioning often does not reach providers.

Social capital

- Local 'social capital' – i.e. the relationships, knowledge, informal arrangements through which 'things are done' - is a key resource for service development. The local knowledge needed to build effective services is subtle and not easily codified.

- The local tensions, contest and resistance to change are a part of 'social capital'. Workforce change should aim to resolve local conflicts to harness local collaborations. Bringing in an outsider provider is often a short-term solution, which erodes local resource.

- Systems of commissioning and contracting need to sustain and build on local relationships and knowledge. They need to facilitate teamwork and provide incentives and structures for secondary and primary care clinicians and managers to work together to take services forward.

- Flexibility is needed to allow providers to use local knowledge and relationships to develop service systems and adapt them to shifting circumstances. Arrangements locked by contracts are not flexible enough. Ways of contracting which allow this flexibility are required. Two possible models were discussed. One model is to contract a provider to operate a

clinical network with a mandate to make changes and adjustments to arrangements. Another model is to establish a boundary around a service and allocate a budget, giving clinicians and managers the mandate to redesign the service to address local issues.

Contestability

- The contestability policy impacts on service development in a number of ways. It can fragment services and disrupt local relationships which sustain services. 'Cherry picking' services, which local NHS providers have built up can undermine local expertise and commitment.

- The impact of competition on service development, and the relationships between providers and commissioners at PBC level need to be clarified.

- Outside private providers can also be a local resource.

The need for training

- Nurses are an underused resource of clinical engagement and participation in service development. They often lack the resources, support and contacts to take a full part in service development.

- Commissioners, managers and providers need training, evidence and support to make the commissioning and contracting systems work to enhance and sustain flexible systems of care for people with LTCs.

11.3.3 Roles and training

Objective 3. To understand the infrastructure, support and training required successfully to achieve appropriate workforce change in delivering respiratory care.

What is the role of the respiratory GPwSI?

- Would a definition of a GPwSI be helpful?

- Suggested roles included assessing referral pathways, as 'movers and shakers' in the local healthcare community, to contribute to strategic development from a different perspective to consultants.

- One of the difficulties is that GPwSIs are predominantly individuals who want to be a GPwSI; there is little (or no) strategic planning at PCO level that assesses local need and local differences.

- Respiratory care is an area where the patient's context is very important – in this respect it is perhaps different from specialties which lend themselves more to protocols/algorithms.

- GPwSIs are an expensive resource because of the need to backfill their (expensive) practice time and because of the new contract which means that they are often more expensive than a consultant; is this the best use of NHS funds? The initial drive for GPwSIs came at a time when incentives were needed to retain GPs; is this still the case?

Bridging the gap between primary and secondary care

- There are still strong barriers between primary and secondary care, often related to misunderstanding of each other's perspective. Much can be gained by seeing how other members of the wider team work.

- GPwSIs could be a valuable bridge between the two sectors.

- If the GPwSI is seen as a champion for better respiratory care, this might encourage consultants to support the role. However, issues remain, e.g. suspicions that GPwSIs are trying to be 'mini-consultants'.

The importance of broader skills (not only clinical skills)

- The three functions of a specialist service (clinical, educational, strategic/leadership) described in the presentations resonated with participants.

- GPwSI formal accreditation is important in terms of credibility with colleagues but other qualities are very important: enthusiasm, drive, the ability to provide a service, leadership and good people skills including the ability to educate others and to encourage good teamwork.

- Training courses therefore need to assess these important personal transferable skills to ensure that by the end of the course the individual is not only skilled clinically, but has also developed these skills. Some courses currently incorporate training in service redesign, negotiation skills etc (e.g. through a simulated PEC meeting).

- Medical education is increasingly emphasising generic skills (e.g. communication, team-building) and so the 'next generation' of doctors should be better equipped with these skills.

Training programmes for respiratory GPwSIs

- Respiratory GPwSIs tend to be less clinically focused than, say cardiology GPwSIs, making it hard to devise a framework for all specialties.

- Training needs to be flexible enough to harness individuals' enthusiasms and interests and accommodate different learning styles. However, there needs to be a degree of harmonisation in terms of competencies.

- It is also essential that individuals go on developing their competencies throughout their career: the emphasis on competency-based training for accreditation must not be seen as the end of the process.

- On-going support and mentoring (e.g. from a consultant) and on-going peer updating are essential in addition to formal training. Participants suggested that a mentor had several roles: educational facilitator; friend/colleague; coach and clinical competence 'backstop'.

Training needs of other health professionals working in respiratory care

- All health professionals need to maintain competence. Suggestions included highlighting and addressing 'inappropriate' referrals, providing

mentoring for practice nurses (as is required in secondary care under 'Agenda for Change').

- Education should explicitly train health professionals to work in teams; at present, much of this training is subliminal rather than explicit.

- The demographics of the nursing population (around 25% due to retire in the next five years) mean that there is an urgent need for 'succession planning' so that these skills are passed on to younger nurses.

- There is a Working Framework of nursing competencies but it cannot be enforced in primary care as GPs are independent contractors, and so primary care nurses cannot use it to argue for training, or as justification for post-training pay increases. How should this be addressed?

- It is difficult to emphasise respiratory training in primary care when primary care health professionals have so many other areas they need to be competent in (e.g. leg ulcers, depression etc).

Training needs of PCO commissioners

- Following World Class Commissioning, some PCOs have put commissioning out to private companies as they did not have the skills in-house. This suggests a substantial skills deficit at PCO level.

- PCO staff may be performance-managed on specific targets (e.g. reducing bed days). PCO commissioners may know very little about any one disease area, or may be moved on to another disease area as soon as they have become familiar with one. Commissioners may wish to make wider improvements in respiratory care (e.g. provide more training for practice nurses, appoint a GPwSI etc) but may be unable to map out the next steps (e.g. know what services can be adjusted in order to release a budget, know who the local people with influence in the respiratory field are). These deficits can be addressed by training and by better communication with respiratory clinicians (e.g. GPwSIs).

The skills and service deficits in respiratory care

- There is not currently the skill base to deliver what the NSF intends.

- Poverty of expectation: the big emphasis is on keeping patients out of hospital and so most efforts are directed towards that. Yet there is a huge amount of unmet need in respiratory disease; participants commented that it is odd that public health clinicians are not pushing this very hard in view of the high levels of morbidity and mortality.

Funding for education and training

- Participants debated whether the employer (e.g. primary care) should fund education and training to ensure that the employee is able to provide what the service is offering. Alternatively some courses (e.g. Masters degrees) may be down to the individual. In practice the division was not clear cut. Education at supra-practice level enabled economies of scale.

- Private companies tend to invest around 10% of their budgets in staff training and it might be useful if the NHS thought in terms of this percentage and considered investing in cross-NHS training to ensure that the service as a whole had the skills needed.

- Many training departments were reduced in size as part of the reorganisation of Strategic Health Authorities. With reductions in training budgets, pharmaceutical companies have stepped in. What are the implications of this?

- The additional funds for being a Teaching PCO are minimal (around £50,000) so there is little incentive for PCOs to take on this role or to develop innovative or comprehensive provision of education and training.

The impact of PbR and PBC on training and education

- Some managers are forbidding consultants to go out and train practices as it is not paid for under PbR.

- PbR and PBC were thought to have changed practice in that 'mistakes' were now more likely to be noted as a reason not to contract with that provider in the future, rather than as a trigger for informal education and discussion as in the past.

Failure to learn from significant incidents

- 'Significant incident' reviews were a potentially valuable opportunity for education and training, but were often used to 'tick boxes' (e.g. for QOF) rather than to foster learning; it was rare for significant incident reviews to involve the whole team or to cross primary and secondary care and hence valuable learning opportunities were lost.

11.3.4   Patients and citizens

Objective 4. To examine the relationship between changes in respiratory services and patient experience when respiratory services are reconfigured

Objective 5. To examine patients' awareness and perception of workforce changes in the context of overall management of their respiratory disease

Patients are a valuable resource and their involvement is imperative to effective and appropriate service design and planning

- In terms of knowledge management and organisational memory, patients are a good source because they experience the changes and are able to make statements about what organisations used to be like.

- Interaction of patients and people with management and service redesign expertise is useful in order that patient views are not seen in isolation.

- Being involved provides the possibility of gaining insight into the reasons behind the changes. Patients get frustrated when they feel communication stops once services have been redesigned, and when what they had before has suddenly changed and they do not know why.

Barriers to patient involvement, including the current lack of visible impact of patient views on service design, need to be addressed for true patient participation in strategic planning to be realistic

Consultation fatigue

- Public and patient involvement will not work unless services act on what they propose. If patients and members of the public feel that their views are not consulted, or they do not see any impact they will lose motivation.

- Lip service is paid to patient involvement: health services currently are more concerned with numbers than with patients.

- Patient complaints and suggestions are not really taken into account. People need to feel valued in order for them to take the initiative to voice their opinions.

Lack of awareness

- Patients do not always know what they want, partly because they do not always know what is on offer. Better and more accessible information needs to be available for patients on how to get involved and the issues at stake.

- It is unrealistic to expect people to voice opinions or make decisions without full understanding of the context that health professionals take for granted.

- Realistically patients can bring a patient perspective but not represent patients as such. They can represent their experience of their illness which is valuable but is it enough to make decisions?

Lack of transparency

- Patients need to know to what extent their views will have an impact. The current system does not provide feedback to patients letting them know how much of their input will be taken into account and why certain aspects cannot be taken into account.

- More honesty is needed to ensure that patients have realistic expectations of the impact and use of their input.

Methods for including patients' views and concerns exist in the form of support groups, foundations and public meetings; however, structural and motivational barriers may inhibit their effectiveness

- Breathe Easy Groups do a lot of lobbying to persuade PCOs into shaping the services into what is most appropriate, in particular concerning the availability of pulmonary rehabilitation. However the groups have difficulties in sustaining membership and enthusing new members to join.

- From a structural point of view, emphasis needs to be laid on the support, development, nurturing and paying of various expenses for volunteers in order to ensure the sustainability of support groups.

- Patient foundations need to be proactively approached when service redesign is being considered locally so that the information about changes can be disseminated amongst members.

- Citizens' juries are a possibility of engaging patients but need to be approached with caution and supplemented with other methods in order to ensure genuine consultation.

- Health space, allowing patient access to their own records and hand-held records that can then be transferred between agencies and hospitals can be empowering for patients.

- Service planners may lack motivation to take part in public meetings as they perceive that they 'have heard it all before'.

While self-management is an important aspect of care, it is important to recognise and address the variability of patients and their needs and take into account the importance of flexible and regular access to providers, regardless of the severity of the illness

- It was suggested that patients may appreciate the 'management' aspect but not the 'self' aspect since the term implies that they have little contact with anybody that can support them with it.

- It is important to refrain from seeing patients as a homogenous category. They vary in their needs over time, both from the medical and also the social care point of view.

- Action plans seem to work as they define a 'contract' between patient and provider and thus avoid the danger of patients feeling abandoned to self-care.

- People value contact, continuity and communication about their condition. It is about personal contact and relationships with both the primary and secondary level. Communication is key.

- There needs to be a more preventative focus to self-care. Patients need to be supported before they get to the top of the pyramid.

Training of providers and patients needs to focus on securing and encouraging better communication

- Despite the fact that communication is taught at medical school more emphasis could be laid on recognising the variability of patients' needs and ways of dealing with their condition. In this sense, practitioners need to be able to recognise the appropriate response for each individual.

- In order genuinely to engage in partnership with patients, practitioners need to let go some of the power but also take the different personality types into account. Training programmes need to reflect that.

- Patients need to be equipped to have an informed and effective dialogue with their providers. Information needs to be available in the most accessible form.

Increasing fragmentation of care and lack of continuity?

- The situation in Scotland without an internal market seems less fragmented and less divisive. PBC and payment by results in England often seem to be pulling in opposite directions. With the GP no longer in charge of the co-ordinator of care role, the issue of dealing with co-morbidities is challenging.

- Many practitioners see the creation of the GPwSI and other new roles, including the community matrons as political moves that go in and out of fashion.

- It was suggested that there may be a need for a national respiratory strategy in England which seems to be lagging behind the rest of the UK. Northern Ireland is publishing a service framework for consultation for respiratory conditions. Wales is talking about care pathways and local respiratory action plans, Scotland has standards for asthma care in children and there is a growing campaign for a national respiratory strategy.

12 Implications

12.1 Implications for policy makers

12.1.1 Longer-term objectives

PCOs need to be encouraged to invest in the care of patients at all tiers of the LTC pyramid to achieve long-term benefit.

Policy makers should consider and, if necessary, address:

- The financial imperatives and current policy which have led to specialist services with a narrow focus on the care of people with complex needs in order to reduce admissions in the short term.

- The incentives required to encourage PCOs to invest in specialist services which address the care of people at all tiers of the LTC pyramid to achieve long-term benefit.

12.1.2 Supporting networks

Building effective and sustainable networks is a pre-requisite for the introduction of new ways of working to deliver integrated services for people with LTCs.

Policy makers should consider and, if necessary, address:

- The infrastructure required in order to enable PCOs to develop effective local networks.

- The training required by patients, commissioners and clinicians to enable them to contribute meaningfully to a local network.

12.1.3 Commissioning

Policy makers should review the impact of organisational change and commissioning and contracting, together with the policy of contestability, on systems of care for people with LTCs. Mechanisms to ensure flexibility in cross sectoral relationships need to be built in to systems of commissioning.

Policy makers need to review, consider and, if necessary, address:

- The potentially disruptive impact of successive cycles of organisational change and conflicting policies.

- The potentially disruptive effects of contestability policies on local systems of care.

- The potential loss of flexibility for local services from a commissioning process that emphasises short-term contracts and prioritises contestability.

12.2 Implications for commissioners and healthcare professionals

12.2.1 Teamwork

Harnessing local skills and brokering productive relationships with and between healthcare professionals from both primary and secondary care in order to build effective and sustainable networks is a pre-requisite for the introduction of new ways of working to deliver integrated services for people with LTCs

Clinicians and managers driving workforce change and commissioning new services for people with LTCs will need skills that enable them to:

- Identify clinicians with core skills to contribute to service development.

- Support professional development of potential clinical leaders, including encouraging mentorship arrangements which should be seen as furthering crucial relationships as well as providing training.

- Identify and address local conflicts of interest which can disrupt developments. Negotiation to enable alignment of visions, and ensuring collaborative advantage are key strategies.

- Address the systems' level barriers that prevent specialists being fully effective in their new roles (e.g. referral barriers between specialist nurses and medical services).

- Build, nurture and ensure the sustainability of networks involving all stakeholders (including representatives of primary and secondary care, medical and nursing disciplines, managers and patients).

Such networks, underpinned by supportive relationships have the potential to:

- Mitigate the disruptive impact of change, organisational reform, and financial crises.

- Facilitate the integration of care across existing organisational and professional boundaries.

- Allow the evolution of new roles by providing an environment in which professionals can be supported to develop new skills and in which their new roles are accepted.

- Reduce the fragmentation of services which may result from commissioning bundles of care, as personal relationships and common visions between professional groups enable the development of care pathways in which the service components are interwoven.

- Provide strategic direction to the provision of care for people with LTCs, ensuring that services not only address the clinical needs for people with complex needs at risk of admission, but also accept an educational and quality assurance role for patients at all levels of the LTC pyramid.

- Share knowledge and development, ensuring that the network stays informed of best practice.

12.2.2   Training

Training for GPs and other clinicians with special interests, and managers commissioning services for the care of people with LTCs should provide the broader skills required to work strategically within networks

- GPwSI and other new specialist roles need to be prepared for a strategic and educational role as well as provide clinical training. Specifically, they require an understanding of the commissioning process.

- Nurses (and others) need training and support to develop networking and leadership skills to enable them to play a full role in the design and provision of specialist services.

- Training for commissioners and PCO managers should include a focus on the skills required to identify and harness individual clinical talent, recognise and manage the complex inter-professional issues and build and nurture local clinical networks.

- Health professionals, commissioners and managers need training to enable them to involve patients and the public in the planning and evaluation of services.

12.2.3   Flexible access to services

Systems of care for people with LTCs (such as respiratory disease) need to encourage flexible access and movement between self-care and professional services. The increasing diversity of professional roles and tendency for commissioning to create services targeted at separate 'packages' of care, introduces complexity for both patients and clinicians. Simplification of systems, clear signposting and co-ordination of individual patient care from a key trusted professional are essential.

Flexible access and effective communication across the boundary between self-care and professional services is crucial at all levels of the LTC pyramid (see section 10.3.5) to support patients and prevent a sense of 'abandonment'.

Flexible access to professional care:

- implies services delivered in a timely manner by an appropriate professional and at a suitable location

- recognises that different modes of consultation (e.g. face-to-face, telephone, e-mail) will fulfil different needs (e.g. provision of information, on-going support, acute care etc)

- acknowledges the importance of being able to draw on the skills of different professionals during the course of a long-term condition, whilst emphasising the importance of a trusted key professional to co-ordinate care.

12.2.4 Patient involvement

Patients need to be supported to enable their awareness of and interest in the changes in delivery of their care to be harnessed enabling them to contribute meaningfully to decisions about service development

12.3 Implications for research

Commissioning

We observed that commissioning, with its targeted focus on cost effectiveness of services, disrupted the existing local relationships which underpinned overall service arrangements.

There is a need for further research:

- To understand the immediate and long-term impact of the current formal commissioning and contracting processes on workforce reconfiguration and service provision, including their impact on workforce morale.

- Specifically to understand the impact of PBC on local service development, including breadth of service provision across sectors.

- To test how the social capital can be identified and described in specifications so that it is sustained/retained, no matter what commissioning or contracting process is in place.

Professional boundaries

We have captured the way that professional boundaries are being redrawn as new roles are emerging to provide intermediate care services within a market based NHS.

There is a need for further research:

- To understand the longer-term impact as these new professional roles evolve and become established.

- To compare the impact of similar workforce changes in different disease areas and involving a more diverse range of professionals.

- To understand the boundaries between clinicians and managers, and the impact on boundaries among managers of increasingly diversified manager functions among and between providers and commissioners.

Clinical networks

We have highlighted the importance of teamwork, and also the skilful management involved in overcoming the challenges of local circumstances,

existing relationships and personalities to build effective teamwork built on collaborative advantage.

There is a need for further research:

- To understand how clinical networks can be facilitated, their optimal membership and what level they should operate within the NHS

- To understand the impact of clinical networks on services commissioned for LTCs, local workforce morale, capacity and development.

Training

We have shown that, in addition to the currently available specialist clinical training, GPwSIs and other professionals in new roles have identified the need to learn strategic and leadership skills. We also suggest that training for commissioners should include an emphasis on brokering relationships and nurturing teams.

There is a need for further research:

- To understand the extended training needs of healthcare professionals to enable them to fulfil the educational, and strategic roles of providing a specialist service.

- To understand the training needs of commissioners to enable them to develop and work effectively with local clinical networks.

Flexible support for self-care

Patients emphasised the need for flexible support at the boundary between professional and self-care.

There is a need for further research:

- To understand and evaluate ways of providing flexible support for people with LTCs to enable self-care, including promoting health literacy, flexible access to primary, intermediate and secondary care advice, and the roles of different modes of consultation.

- To understand how a commissioner would evaluate that flexible support was available in the contracted services.

Involving patients

Despite being aware of changes in the availability and type of providers affecting their personal experience of care, and interpreting these in the light of regional and national events, patients were not actively involved in service redesign.

There is a need for further research:

- To develop strategies to address the widely acknowledged barriers to patient and public involvement in order to harness this untapped resource.

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Appendices

Appendix 1 Screening interview schedule

Schedule for the initial semi-structured screening interview with the person responsible for driving the reconfiguration of respiratory services.

Background information

Size of PCO:

Demographics: urban, semi-urban, rural, remote; areas of deprivation.

Workforce issues: GP vacancies, Consultant vacancies, nurse/physio availability.

Any specific local issues (unemployment levels, significant local employers competing for potential employees, local availability of training – university/colleges etc)

Plans for PCO reconfiguration: which are the proposed 'partner PCOs'?

What are the key priorities for service redesign in your PCO?

[Specific prompts: Key issues that affect service redesign, PCO's approach to the management of long-term diseases, how do respiratory services fit in with the overall strategy?]

Does your PCO have any plans to develop services for people with respiratory disease?

If yes:

Please outline what service development is being considered or is already underway.

[Specific prompts: respiratory GPwSI, respiratory specialist nurse, Evercare/other managed care project, COPD Primary Care Collaborative, developing existing primary care/supporting GMS contract, secondary care outreach, Hospital at Home scheme, providing specific services (spirometry, pulmonary rehabilitation, palliative care for COPD allergy)]

Why is the PCO considering these changes?

[Specific prompts: pressure on secondary care, primary care collaborative, strategic development of care for long-term conditions, pressure from a primary/secondary care respiratory champion, pressure from patient groups, SHA/national pressures]

[Any local information driving these decisions: referrals, waiting times, asthma and COPD admissions, prescribing costs]

[Any evidence informing these decisions: published literature, NatPact/ BTS/NRTC/GPIAG/other resources, experience in neighbouring PCOs]

What are the priorities to be addressed by the reconfigured service?

[Specific prompts: reducing admissions, raising quality of primary care, reducing outpatient referrals, providing spirometry/pulmonary rehabilitation/palliative care for COPD/allergy services]

Who is responsible for driving changes (if any) in the provision of respiratory care, and/or other chronic disease areas?

[Specific prompts: PCO manager, primary/secondary care clinician]

[Other key players?]

What workforce changes will be needed to realise the planned development?

[Specific prompts: new appointments (GPwSI, specialist nurse/physio/other, healthcare assistants) new skills for existing staff (extending the skills of nurses/physios/healthcare assistants/other]

What training is planned for this reconfigured workforce? [Specific prompts: formal training (MSC, degree level, diploma level course, mentoring with local primary/secondary care clinicians, NRTC/RETC/other accredited training organisations/pharma-sponsored training]

[Basis on which appropriate training was identified/chosen: formal needs analysis, clinician's own preference, managerial decision, personal recommendation, official requirement]

[Accreditation/appraisal arrangements: local arrangements, following national guidance]

What are the barriers?

[Specific prompts: lack of suitable candidate(s) for new respiratory GPwSI/respiratory specialist nurse/physio/other posts, no funding for the new post, no funding to support training, opposition from primary/secondary, clinicians/PCO management/patients, competition with other priorities]

What sources of information and support have been accessed?

[Specific prompts: published literature, web-based advice e.g.NatPact/BTS etc, informal advice from colleagues]

What monitoring is planned?

[Specific prompts: COPD/asthma admissions/bed days, outpatient referrals, A&E attendances, PACT data, quality and outcome framework returns from the practices, referrals to new services]

What effect will the planned PCO reconfiguration have on these plans?

[Specific prompts: existing services/plans/respiratory champions in 'partner' PCOs, effect of uncertainties due to the reconfiguration]

Any other comments?

If no:

Please outline why reconfiguration of respiratory services is not a priority in your PCO.

[Specific prompts: existing primary/secondary service is very good, addressing the issues in other ways (what other models – e.g. generic Chronic Disease Management nurses) other priorities (what are these priorities and why?), no identified local need (what is this based on?), no local interest from clinicians]

[Factors that would change the priority attached to respiratory care: local data suggesting there was a problem, national/SHA directives, local interest/availability of specialists, identifiable funding stream]

What sources of information and support do you regularly access to help you develop services?

[Specific prompts: published literature, web-based advice e.g. NatPact, informal advice from colleagues]

What monitoring of respiratory services is routinely undertaken or planned?

[Specific prompts: COPD/asthma admissions/bed days, outpatient referrals, A&E attendances, PACT data, quality and outcome framework returns from the practices]

What effect will the planned PCO reconfiguration have on these plans?

[Specific prompts: existing services/plans/respiratory champions in 'partner' PCOs, effect of uncertainties due to the reconfiguration]

Any other comments?

Thank you for helping with our research.

The information you have given us will help us understand how respiratory care is being developed around the country. In the next phase of this project we will be recruiting 6 PCOs who are planning different models of care to take part in an in-depth case study over the next year. If we think that your PCO would be a particularly useful example for our study, please may we approach you again to see if you would be interested?

Appendix 2. Screening interview coding frame

Role of the interviewee

Duration of post, experience, timescale, positive and negative experiences of service models

PCT situation

Context, and the impact on service development
• Mergers
• Budgets
• Geography

Development of models of care

Process of selecting, and developing new model of care
• Champions
• Managed
• Evolved
• Patient need

Why

Why this model of care? History of the adopted model
• Money
• Quality
• Competencies
• Serendipity/other (ie. geographic, demographics etc.)
• Patient need – how is this known?

Roles

New roles adopted, including any tension within/between roles, specialist/generalist contribution
• Consultant
• GP role (GPwSI, interested GP, no GP involvement)
• Nurses (Specialist, Intermediate care, Community matron
• Managers
• Patient involvement

Functions of the service

What functions does the service fulfil?
• Clinical roles (including preventing admissions, pulmonary rehabilitation, other clinical services
• Educational functions
• Strategic roles

Integration of Care
• Is it a third tier?

- Communication channels
- Integration
- Community
- Co-morbidity
- Specialist vs. generalist –where do the roles fit?

Training

What training, accreditation? Approach to competencies?

Teams

Involvement of stakeholders in the process of service reconfiguration
- primary care
- secondary care
- PCO management

Appendix 3. Case study topic guide

Initial 'baseline' interviews

The content of these semi-structured interviews was dictated by the circumstances within the PCO and the role of the interviewee. The overall aim was to build on the 'snap-shot' provided by the initial telephone interview to develop a detailed picture of respiratory services in the PCO and any proposed plans for development from the perspective of key players in service development.

The interviews included:

- The history of the respiratory service within the PCO and any previous developments (successful or otherwise).

- The current service and any perceived strengths and weaknesses.

- Any data or local evidence to support these perceptions.

- Current local workforces issues such as numbers of doctors and nurses working in respiratory medicine; unfilled posts, skill mix arrangements, problems with recruiting.

- The aims, and expected benefits, of the proposed service.

- The current plans for development, and the progress to date. Further interviews were sought with any key stakeholders identified by the initial interviews.

- The attitudes to the projected plans and perceived advantages and disadvantages

- Alternatives either rejected or still under discussion.

- The evidence (including financial/clinical evidence, local/national data) used to inform proposed plans and any advice and support accessed.

- The factors perceived to be facilitating progress and actual / potential barriers to development.

- The immediate plans for making progress towards service reconfiguration (e.g. planned meetings, audit activities, training programmes, new staff appointments, planned explorations of available resources / advice / support agencies etc).

- The training needs, from the perspective of the healthcare manager responsible for developing the service and, importantly, with the GPwSI.

- The anticipated effect (if any) of PCO merger and the implementation of PBC.

Follow-up interviews

The content of the follow-up interviews was largely dictated by the specific circumstances, and key events that had occurred since the previous interview in each of the PCOs.

How have events moved on in the last few months?

Follow-up key initiatives in each PCO. For example:

> GPwSI service and relationship with Hospital Trusts in Merged PCO

> Acquisition of funding for expanded services in Team PCO

> PCO reorganisation and function of the Clinical Reference Group. Role of GPs and PBC Groups in Commissioning PCO.

> Appointment of second Community Specialist Respiratory Nurse in Rural PCO

What has been the effect of

Upheaval and change on workforce/service development

Mergers and reorganisation

Financial: (deficit / balance, etc)

PCO funding processes

What is the process by which the PCO prioritises commissioning?

What are the mechanisms by which initiatives get funded (formal / informal)?

Who else could answer this?

Anyone else to include who's involved with respiratory care, especially with reconfiguration of services?

Appendix 4. Case study coding frame

All nodes are free nodes; the bullets below them are examples of what we might include within them but these lists are not exhaustive

Description: Local model or service arrangements, co-ordination of care
- Discharge and care in the community
- Informal feedback about local service
- Out of hours service
- Possible developments
- Recruitment issues
- Respiratory team
- Rural areas
- Sole provider within PCO
- Sustainability
- Vision for the future
- Co-morbidities and complexity of care
- Fragmented service
- Holistic care
- Integrated care
- Intermediate care
- Managing or tracking care and patient information

Change
- Catalyst for change
- Change and continuity of team working
- Coping with uncertainty around change
- Critical mass
- History of change
- Impact of other service changes (e.g. mergers)
- Impact on staff of change
- National policy
- Turbulence

Commissioning and markets
- PBC (Practice-based commissioning)
- Priority setting by PCOs
- QOF

Cost, funding, resources, pricing

Governance
- Accountability
- Dealing with clinical uncertainty
- Safety
- Trust

Performance measurement and audit

Professional boundaries (clinical and managerial) and personal relationships
- Competing - GPs, consultants & nurses
- Consultant redundancy
- Respiratory nurse vs community matron
- Specialist nurse vs GPwSI
- Transgressing traditional roles or boundaries
- Opinions about the GPwSI model in general
- Relationship between GP and consultant
- Relationship between secondary care consultant and the PCO
- Relationship between the respiratory service and consultants
- Relationship between the respiratory service and GPs
- Tensions
- Tensions between Trust managers vs clinical staff
- Generalist vs specialist
- Bravery & risk
- Champions
- Individual's personal credibility or reputation

Training and accreditation

Critical factors for success

Evidence

Patient mentions

Image of respiratory medicine

Appendix 5. Extract from an illness diary

1.   Instructions

How to keep an illness diary.

We would like you to keep a diary of your respiratory illness for one month.

Find a convenient time each day when you can spend 5 or 10 minutes writing in this diary.

What you write in the diary is up to you, but some ideas include:

- Any symptoms you have had that day, and any treatment you have used.

- How your respiratory illness has affected your life that day.

- Any advice and information you read in magazines, on the internet, or saw on television.

- Any discussion about your illness with friends or family.

- Any consultations about your respiratory illness with your GP, nurse, hospital consultant, pharmacist.

- Any consultations with a complementary therapist about your respiratory illness.

Although there are two pages for each day, we do not expect you to fill it up every day! Sometimes your respiratory illness may cause you no trouble and there will be very little to record. Other days you may have seen your GP, discussed your respiratory illness with a friend, read something in a magazine or had to change your plans because of your symptoms. On these days you may want to write more in the diary.

I have a question

Tara Kielmann will be pleased to answer questions. Contact details*:* Tel: 0131 650 9238

  E-mail: tara.kielmann@ed.ac.uk

Division of Community Health Sciences: GP Section, University of Edinburgh, 20 West Richmond Street, Edinburgh EH8 9DX

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2. **Sample page**

DAY 1.   Date:

On a scale of 1-10 how would you rate your respiratory health today? (1 = very poor; 10 = excellent)

1   2   3   4   5   6   7   8   9   10

Please describe why you have chosen to rate your respiratory health in this way?

What kind of actions/activities did you do today that were related to your respiratory health (consult a health provider, talk to friends or family, use any treatment, etc.)?

In what ways did these actions/activities help you and why/why not?

Is there anything else that you would like to mention in relation to your health today (news articles, specific advice, decisions, thoughts, type of care, etc.)?

Appendix 6. Patient interview topic guide

Dealing with the condition

Who have you consulted about your condition recently?

How did you first get in contact with the health providers? How did you enter the system? What did you think about the encounter? What did you hope to gain from the encounter?

How easy/difficult is it for you to communicate with your health providers (can you discuss issues, your worries etc.)?

What other sources of support do you have (social services, friends, family, patient groups)? Do you know anybody else with your condition?

How do you deal with your condition in everyday life? How has it affected you recently?

Integration of care

How do you know whom to see?

Who does what for you? Who do you see for other medical problems? (maybe draw on map of providers to develop story)

Do you feel that they (specific providers) communicate well with each other when it comes to responding to your needs?

What do you expect from the health services in your area? Is there anything you can think of that the health services should be providing locally for people with your condition?

Self-management

How do you gain knowledge about your condition (i.e. clinicians, internet, newsletters, library, friends, etc)? How do you know which sites to navigate?

How easy/difficult is it for you to access the health services?

How much in control do you feel over your condition?

Do you feel comfortable making decisions on your care (i.e. changing the dose/starting or stopping medication) on your own?

Knowledge about service changes

How has your care changed over the last couple of years? Have you noticed any changes in the services you receive?

Have you noticed any new professional roles – in what sense are they different to your experience before?

Who (else) do you know in your area who provides specialist care? (E.g. the GPwSI, specialist respiratory nurse, community matron)?

Pick up on any issues that stand out in the illness diaries.

Pick up on any issues that stand out in the illness diaries.

Appendix 7. Focus group topic guide

Introduction: welcome, introduction to us and to each other, brief recap on the study, anonymity and confidentiality, the format for the session, agreement to taping, any questions before we start.

What services are you aware of and use in relation to your respiratory health?

(Let each participant describe. Will help the group become attuned to their experiences of their service use. Maybe draw map with different providers to visualise things.)

Prompts: Different types of health staff, schemes (i.e. managed care, hospital at home, pulmonary rehab)

How does this local system work for you? And for other people you know with respiratory disease?

(What interests us should come out in discussion. If not, we can ask about our concerns towards the end of this part).

Prompts: Relationships with providers; ease of access; availability; quality; awareness of specific new local services?

Are you aware of any current changes or developments in respiratory services in your area?

(This is an opportunity for members of the group to exchange knowledge and experience. We should let this take place with minimal interference).

Prompts: Changes in care patterns; referral patterns; new professional roles; schemes)

What are the most important parts of a service/system for you?

How would you like services in your area to develop?

Prompts: preferences for service development; priorities; unmet need and how to tackle; visions for future development

NB We are interested in:

Participants' awareness of and experience of current, past and changing services

Attitudes towards specific innovations e.g. GPwSI

Preferences for who should deliver care and attitudes to substitution of traditional providers

By the end of the session, we aim to have key ideas from the group on a flip chart that participants can agree is a record of the main issues for them.

Appendix 8. Patient perspective coding frame

Dealing with the condition
- Effect on everyday life
- Sources of support
- Carers
- Co-morbidities
- Descriptions/perceptions of self
- Descriptions/perceptions of condition

Integration of care
- Communication between health staff
- Stories on navigations through the system
- Mention of referrals

Self care
- Ways of managing the condition without health staff
- Information sources
- Complementary therapists and alternative treatments

Perception of health services
- Access, availability
- Quality
- Communication, relationship and perceptions on staff
- Communication with and perceptions of staff

Knowledge and awareness of service developments
- Mention of new professional roles
- Mention of new service developments
- Description of local/regional services
- Mention of changes in care

Patient needs
- Mention of practical needs
- Desire for service changes

Appendix 9. Workshop discussion groups

Policy and practice

To identify key drivers of respiratory service reconfiguration in a sample of PCOs

The key drivers identified by our screening and case study PCOs were the policy for providing care closer to home for people with long-term conditions and the imperative to achieve financial balance. The impact of this in practice was an almost exclusive focus on clinical services for people with COPD at the top of the Kaiser Permanente pyramid. Where successful teamwork between PCO managers and both primary and secondary care clinicians was achieved it was highly valued, and was associated with a fruitful alignment of objectives and a broader approach to clinical, educational and strategic aspects of respiratory service development.

Are our conclusions correct?

- Does your experience support, or refute that conclusion?
- Can you give examples (from respiratory, or other LTCs)?

Is it appropriate that specialist services should focus on all levels of the LTC pyramid?

- If yes, who should address the needs of all severities of patients (e.g smoking, mild COPD/asthma)?
- If no, are the suggested functions of a specialist service (clinical, educational, strategic) an appropriate framework for PCOs commissioning services for LTCs?
- Can you give examples from your experience? (from respiratory, or other LTCs)?
- Should the commissioned services extend to other respiratory conditions? (which?)
- How can we as clinicians broaden the emphasis of commissioning?

What is/should be the role/contribution of PCO commissioners, primary and secondary care clinicians and patients in driving service reconfiguration for long-term conditions?

- What constitutes an appropriate relationship in the commissioning process?

Commissioning and clans

To identify the factors (including local context, knowledge/evidence base, available resources and perceptions of clinical roles) which shape the planning and implementation of workforce change

The process of service reconfiguration and accompanying workforce change we observed was complex, fluid and often fortuitous. The most important factors were the context of the service arrangements, and the way this shaped relationships between clinicians and managers who were

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instrumental in carrying them through. Service arrangements which had the support and engagement of clinicians and managers in both secondary and primary care, and which facilitated an alignment of interests, were best able to drive comprehensive service change. The emerging commissioning structures impacted on relationships, with the potential to disrupt arrangements sustaining existing models.

Does this picture resonate with your experience?

- Can you give examples (from respiratory, or other LTCs)?
- Can we reasonably extrapolate from respiratory to other LTCs?

Are existing local relationships important for service development? In what way – positive and negative?

- How can they be harnessed appropriately?
- How will or is PBC impacting on local relationships driving service change?

How can sustainability be ensured?

How can patients be engaged in this process?

Roles and training

To understand the infrastructure, support and training required in order to successfully achieve appropriate workforce change in delivering respiratory care

Recent DoH advice on accreditation of GPwSIs has focused on the clinical service, providing quality assurance for governance purposes. Our data, however, suggest that the training needs are far broader encompassing management, public health, education, mentoring etc.

Are our conclusions correct?

- Does your experience support, or refute that conclusion?
- Can you give examples (from respiratory, or other LTCs)?

What are/should be the functions of a specialist service?

- Clinical care for those with complex needs?
- Educational to ensure a quality service?
- Strategic to contribute to the strategic development of services?

What are the skills required to deliver those functions?

- How can training needs be assessed?
- How can training be provided in the real world with pressures on time/resources?

Who in the PCO has training needs?

- GPwSIs, consultants? Commissioners, lay advisors?
- GPs, practice nurses?

What is the purpose of mentorship?

- Is it important?
- How can it be facilitated in the 'real world'?

Patients and citizens

To examine the relationship between changes in respiratory services and patient experience when respiratory services are reconfigured. To examine patients' awareness and perception of workforce changes in the context of overall management of their respiratory disease.

Whilst most patients described their awareness and perception of changes in respiratory services in terms of their personal experience, there was evidence that some patients made sense of their experiences in the context of national headlines. Although new roles were often highly prized (especially community matrons or specialist respiratory nurses) by those benefiting from them, long-standing relationships (e.g. with 'their' GP) were also important and lamented when changes in the GP role resulted in loss of co-ordination. Community care was preferred, and generally self-care was welcomed, but discharge from specialist care (or over emphasis on self-care) could create a sense of feeling abandoned. We saw little evidence of patients being actively involved in the development of their health services.

Are our conclusions correct?

- Does your experience support, or refute that conclusion?
- Can you give examples (from respiratory, or other LTCs)?

How can patient involvement with service development be enabled?

- What support and/or training do patients need to enable them to be involved?
- What support and/or training do health professionals and commissioners need to be able to involve patients in developing services?
- How can communication between the NHS and citizens be facilitated to create and maintain successful involvement?

With the increasing diversity of clinical roles, and the move to commissioning to provide specific services, how can continuity of care be ensured?

- Do time limited commissioned contracts pose a threat? How can this be addressed?
- How can discharge from a specialist service be facilitated?

Afternoon session (all four groups)

We are seeking advice on implementation strategies, or practical resources that would be useful outputs from the study. We would like participants to consider both the ways that this might be done and the content of such outputs. Some examples might be: training material for commissioners; a briefing document for MPs; using websites that are regularly viewed by managers or clinicians etc.

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Addendum

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