

Integration and continuity of primary care: polyclinics and alternatives – a patient-centred analysis of how organisation constrains care co-ordination

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***National Institute for
Health Research***

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Abstract

Integration and continuity of primary care: polyclinics and alternatives – a patient-centred analysis of how organisation constrains care co-ordination

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Background: An ageing population, the increasing specialisation of clinical services and diverse health-care provider ownership make the co-ordination and continuity of complex care increasingly problematic. The way in which the provision of complex health care is co-ordinated produces – or fails to produce – six forms of continuity of care (cross-sectional, longitudinal, flexible, access, informational and relational). Care co-ordination is accomplished by a combination of activities by patients themselves; provider organisations; care networks co-ordinating the separate provider organisations; and overall health-system governance. This research examines how far organisational integration might promote care co-ordination at the clinical level.

Objectives: To examine (1) what differences the organisational integration of primary care makes, compared with network governance, to horizontal and vertical co-ordination of care; (2) what difference provider ownership (corporate, partnership, public) makes; (3) how much scope either structure allows for managerial discretion and 'performance'; (4) differences between networked and hierarchical governance regarding the continuity and integration of primary care; and (5) the implications of the above for managerial practice in primary care.

Methods: Multiple-methods design combining (1) the assembly of an analytic framework by non-systematic review; (2) a framework analysis of patients' experiences of the continuities of care; (3) a systematic comparison of organisational case studies made in the same study sites; (4) a cross-country comparison of care co-ordination mechanisms found in our NHS study sites with those in publicly owned and managed Swedish polyclinics; and (5) the analysis and synthesis of data using an 'inside-out' analytic strategy. Study sites included professional partnership, corporate and publicly owned and managed primary care providers, and different configurations of organisational integration or separation of community health services, mental health services, social services and acute inpatient care.

Results: Starting from data about patients' experiences of the co-ordination or under-co-ordination of care, we identified five care co-ordination mechanisms present in both the integrated organisations and the care networks; four main obstacles to care co-ordination within the integrated organisations, of which two were also present in the care networks; seven main obstacles to care co-ordination that were specific to the care networks; and nine care co-ordination mechanisms present in the integrated organisations. Taking everything into consideration, integrated organisations appeared more favourable to producing continuities of care than did care networks. Network structures demonstrated more flexibility in adding services for small care groups temporarily, but the expansion of integrated organisations had advantages when adding new services on a longer term and a larger scale. Ownership differences affected the range of services to which patients had direct access; primary care doctors' managerial responsibilities (relevant to care co-ordination because of their impact on general practitioner workload); and the scope for doctors to develop special interests. We found little difference between integrated organisations and care networks in terms of managerial discretion and performance.

Conclusions: On balance, an integrated organisation seems more likely to favour the development of care co-ordination and, therefore, continuities of care than a system of care networks. At least four different variants of ownership and management of organisationally integrated primary care providers are practicable in NHS-like settings. Future research is therefore required, above all to evaluate comparatively the different techniques for coordinating patient discharge across the triple interface between hospitals, general practices and community health services; and to discover what effects increasing the scale and scope of general practice activities will have on continuity of care.

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Glossary

Italicised terms originate in languages other than English.

Buurtzorg A not-for-profit organisation providing team-based community care, with general practitioner support and a minimal management infrastructure (the Netherlands).

Captant A professional (typically a doctor) who deals with a patient first in each new episode of care, and who by default becomes the first de facto professional co-ordinator of the patient's care.

Care co-ordination Activities that combine different providers' separate inputs into a coherent programme of care for a patient.

Care network A stable set of linkages between separate provider organisations, for the purpose of jointly providing care (e.g. by implementing a care pathway).

Clinical co-ordination Care co-ordination at the level of the individual patient.

Consultation model A method of care co-ordination in which all referrals are made by the professional (typically a doctor, but possibly a nurse practitioner or similar) who co-ordinates a patient's care. Hence, the co-ordinating professional is at the centre of a star-like pattern of referral links.

Continuity of access The range and accessibility of services, compared with a patient's health-care needs, that the patient has access to.

Continuity of care A omnibus term for one or more of the following dimensions ('continuities') of care. See the separate glossary entry for each of cross-sectional continuity, longitudinal continuity, flexible continuity, continuity of access, informational continuity and relational continuity.

Cross-sectional continuity Managing a patient's complex health conditions as a totality in light of how he or she, and the corresponding interventions and care, interact. Synonyms: 'clinical', 'comprehensive', 'holistic', 'management' or 'therapeutic' continuity of care.

Falsificationist (method) A method of testing hypotheses by means of seeking evidence that would show them to be false. Hypotheses that survive this test are provisionally accepted, pending any future discovery of new evidence that disproves them.

Flexible continuity Responsiveness of care to changes in a patient's circumstances.

General practitioner Here, defined narrowly as a primary care doctor who is a co-owning partner in a professional partnership (see below) providing primary medical care (i.e. a particular kind of primary care doctor).

Governance structure A structure by which policy-makers or managers exercise control within organisations and over other organisations: classically networks, hierarchies and markets (but also professional partnerships, democratic organisations, etc.).

Health Passport A patient-held summary of the patient's current health status, medication and other information that a new health-care provider is likely to need to know.

Husläkare Primary care doctor (Sweden).

Informational continuity The extent to which a patient's care plan is decided on the basis of all of the available relevant information from all relevant providers about the patient's history, current condition, circumstances and care needs.

Instantiate To represent, as an example or instance.

Integration Here, defined narrowly to mean organisational integration, that is to say the unification of a number of services within one organisation that has a single structure of managerial control. This definition excludes collaborations between separate organisations.

Longitudinal continuity The maintenance of planned treatment when providers change (e.g. through shift changes, staff turnover or patient transfers).

Nårsjukvard Health centres typically offering planned day surgery, other day treatments and limited inpatient care besides primary care (Sweden).

Nested framework A set of analytic frameworks of increasing generality. The relationships analysed in the first framework (in this case, doctor–patient interactions) take place inside (are 'nested' within) a second, wider framework of relationships (in this case, the ways in which, say, a general practice is organised). In turn, the second set of relationships takes place inside a third, still wider set of relationships (in this case, the external relationships between general practices and other organisations), and so on.

Network A group of three or more legally autonomous organisations that routinely collaborate to achieve a collective goal.

Network co-ordinating (or managing) body A group established to co-ordinate the activities of a care network. Depending on circumstances the co-ordinating body may be a separate organisation or an assemblage (e.g. committee) of representatives from the member organisations, or the role may be monopolised by one of the member organisations (typically the largest or most powerful).

NHS trust In this report the term is used as an abbreviation of the phrase 'NHS trust and/or NHS foundation trust'.

Non-captant A profession or professional undertaking a specific task within a programme of care under the authority of the co-ordinating *captant* professional (see above).

Partnership Defined here in a narrow sense as an organisation co-owned by some or all of those who work in it (the 'partners'), with the organisation being controlled through decision-making among the partners on an approximately equal and democratic basis. (Hence not a care network or other collaboration between separate organisations, although these often call themselves 'partnerships'.)

Person-centred care Care focused on enabling the patient to achieve, as far as feasible, the life goals and activities of daily life to which he or she attaches the most importance.

Polyclinic Also defined narrowly here as a primary care provider organisation that employs and manages salaried doctors and other primary care clinicians on the same basis within a unified management structure. It may also include some specialist and diagnostic services, as in some large US ambulatory care practices. (The term 'polyclinic' within quotation marks means what was locally called a polyclinic, whether or not it corresponded to the definition used in this report.)

Primärvård läkare Primary care doctor (Sweden).

Primary care Health care that patients can access directly or use while continuing to live in their normal home. (In this definition, primary care may be specialised or generalist, covers a wide range of nursing and other non-medical activities and is not equated with primary medical care.)

Primary care doctor Any doctor providing primary medical care, whether a salaried employee, a professional partner or a 'free professional' working alone (hence the inclusion of general practitioners as a special case.)

Provider An individual professional or organisation caring for patients.

Provider organisation An organisation (professional partnership, bureaucracy, co-operative), not an individual, delivering services.

Realist method An approach to analysing policy and its implementation based on the axiom that 'every policy is a theory'. A policy assumes that performing the prescribed action in the appropriate setting will produce the outcomes that the policy-makers desire. 'Action' is taken widely to include such things as setting up new organisational structures. Hence, each policy can be analysed in terms of what outcomes – intended and unintended – the prescribed action ('mechanism') in fact produced in the settings ('context') in which it was actually implemented.

Relational continuity Ongoing contact with the same carers (care co-ordinator, informal carers, clinicians) during the care process.

Vårdcentral A Swedish polyclinic, publicly financed (but diverse types of ownership) and employing primary care doctors and other clinicians.

Vårdval system A Swedish system giving patients a choice of polyclinic by means of voluntary registration (similar to the NHS list system).

List of abbreviations

A&E	accident and emergency	IPCT	integrated primary care team
AHP	allied health professional	IT	information technology
ANP	advanced nurse practitioner	MBS	Medicare Benefits Schedule
APMS	Alternative Provider Medical Services	MDT	multidisciplinary team
BMA	British Medical Association	MRI	magnetic resonance imaging
CCG	Clinical Commissioning Group	NICE	National Institute for Health and Care Excellence
CHS	community health services	NIHR	National Institute for Health Research
CLAHRC	Collaboration for Leadership in Applied Health Research and Care	NP	nurse practitioner
COPD	chronic obstructive pulmonary disease	PCT	primary care trust
CPN	community psychiatric nurse	PHCC	primary health care centre
DDR	Deutsche Demokratische Republik	OT	occupational therapist
DGH	district general hospital	QALY	quality-adjusted life-year
DRG	diagnostic-related group	QOF	Quality and Outcomes Framework
ED	emergency department	RCGP	Royal College of General Practitioners
EHR	electronic health record	RQ	research question
EMR	electronic medical record	SDO	Service Delivery and Organisation
GMS	General Medical Services	SIPA	services intégrés pour les personnes âgées fragiles (integrated services for frail elders)
GP	general practitioner		
GPSI	GP with special interests	SLL	Stockholms läns landsting (Stockholm county council)
H&WBB	Health and Well-Being Board		
HMO	health maintenance organisation	WHO	World Health Organization
HSDR	Health Services and Delivery Research		

Plain English summary

Many NHS patients, especially frail older people, have what we call 'complex needs', that is, many and varied long-term conditions that need treatment and care from more than one service at once (general practice, community nursing, social services, etc.). The better co-ordinated these services are, the more likely it is that these patients will be aware of, and able to use, the range of support needed to maintain their health. This helps people to avoid further illness and hospital admissions and to continue living in their own homes. In recent years the NHS has introduced new organisations and ways of working in order to improve the care of people with complex health needs. These approaches include general practitioner-led health centres, 'case management' (where a community matron or similar co-ordinates patients' care) and (especially in London) 'polyclinics'. We wanted to find out how these approaches compare in terms of improving the co-ordination of patient care across the range of services. We did this by interviewing patients with complex health-care needs, their carers (where appropriate) and their health/social care workers to find out what helps to co-ordinate the care that patients receive and what creates difficulties. We also looked at the Swedish health system to find out how that goes about integrating and co-ordinating care for patients with complex care needs. This suggests that combining general practice and community health services into one organisation is likely to co-ordinate care better than the current separation between general practice and other health services.

Scientific summary

Background

Nearly one-sixth of NHS patients have multiple morbidities. They usually need more extensive and varied health-care inputs than one clinician can provide, besides 'social' care, informal support and sometimes secondary care, all adjusting to changes in their circumstances or health; that is, complex care. How to co-ordinate all the elements of complex care is an enduring problem. In the NHS, the provision of complex care is distributed across several governance structures: general practices (independent and mostly organised as professional partnerships); NHS trusts and foundation trusts (hierarchical public organisations); and local government (responsible for means-tested social care through a quasi-market). This tripartite division, an ageing population, increasing specialisation of clinical services and the increasing diversity of ownership of health-care providers make the co-ordination and continuity of complex care increasingly problematic and salient policy issues.

Research on continuity of care distinguishes six main forms of continuity:

1. cross-sectional
2. longitudinal
3. flexible ('developmental'; sometimes subsumed under 'management' continuity)
4. continuity of access
5. informational
6. relational (or 'personal').

The way in which the provision of complex health care is co-ordinated produces these continuities, or fails to. A growing body of evidence suggests that care co-ordination occurs at, and results from the interaction between, four levels of health-system activity:

1. care co-ordination by patients themselves
2. provider organisations internally co-ordinating the services that they provide
3. care networks co-ordinating the separate provider organisations
4. at the local health-system level, organisations such as Clinical Commissioning Groups attempting to co-ordinate the above interactions as a whole, and exercising external governance over provider organisations and care networks.

In an attempt to bridge its tripartite structure and improve the co-ordination of care, the NHS has experimented with 'polyclinics' or 'polysystems'. Elsewhere in Europe, polyclinics are integrated organisations that provide primary medical care, nursing (including community nursing) and sometimes further primary care services under a unified managerial structure. Existing research on the relationships between governance structures, care co-ordination and continuity of care suggests, on balance, that an integrated organisation containing a wide range of services (above all, primary medical care) may be more likely to favour the development of care co-ordination, and therefore continuities of care, than co-ordination by care network. This research, therefore, examines the ways in which care co-ordination at the clinical level might be promoted by organisational integration, that is, a unified organisational structure to co-ordinate and provide the different services comprising complex care.

Objectives

The research questions (RQs) were:

1. What difference does the integration of primary care into hierarchical governance structures make, compared with network governance, with regard to:
 - continuity of primary care (horizontal integration)
 - substitution of primary for secondary care (vertical integration)
 - the availability of management information about unit costs of care episodes and management costs
 - diversity of primary care services?
2. In the case of hierarchical governance, what difference does ownership make?
3. How much discretion does either type of governance structure allow for managerial discretion and 'performance'? Within each, which managerial practices tend to promote continuity of primary care, substitution of primary for secondary care and diversity of primary care services?
4. Do the answers to RQs 1, 2 and 3 tend to support or refute the predictions (outlined above) about the differences between networked and hierarchical governance with regard to continuity and integration of primary care?
5. What are the implications of the above for managerial practice in primary care?

Methods

We used a multiple-methods design combining:

1. *Assembly of an analytic framework* by non-systematic review of existing research. This directly contributed to answering RQ 4, and indirectly contributed to answering the other RQs.
2. *A framework analysis of patients' experiences of continuities of care* in a maximum-variety sample of care co-ordination mechanisms (contrasting types of organisational structures, care network structures and managerial practice) using patient interview data and, as validation, quasi-quantified patient record data; and comparing the findings with the co-ordination mechanisms described in the organisational case studies. This contributed to answering RQs 1 and 4.
3. *A systematic comparison of organisational case studies* made at the same study sites. For each site, a case study was produced describing co-ordination mechanisms at organisational, care network and local health-system governance level. Applying the above analytic framework, we systematically compared co-ordination mechanisms across sites; that is, across a variety of organisational and network structures. This contributed to answering RQs 1, 2, 3 and 5.
4. *A cross-country comparison* of care co-ordination mechanisms found in our NHS study sites with Swedish polyclinics, which have primary care co-ordination structures not found in the NHS. This comparison was made by means of constructing organisational case studies similar to item 3 above in selected Swedish polyclinics and systematically comparing them with the NHS case studies. This contributed to answering RQs 1, 2 and 4.
5. *Analysis and synthesis* of data using an 'inside-out' analytic strategy. Starting from patients' experiences of care co-ordination and continuity, we inferred how care providers' organisational structures and management had shaped those experiences (and what other factors had done so). We then traced how care networks (and other factors) had influenced the providers' organisation and management; and, finally, traced the ways in which the governance of local health economies had shaped the working of the care networks.

Inclusion criteria

1. Sites for organisational case studies, and (in England) studies of patient experiences, were a maximum-variety qualitative sample of sites, chosen to represent contrasting configurations of integrated organisation and care network. Study sites included professional partnership, corporate and publicly owned and managed primary medical care providers, and different configurations of organisational integration or separation of community health services, mental health services, social services and acute inpatient care.
2. For patients:
 - i. 65 years of age or older
 - ii. with complex health-care needs, defined as at least two of a list of chronic conditions
 - iii. receiving care for at least 1 year before the study from at least two provider organisations
 - iv. living in their own home or with family.

Data sources

1. Patient experience: patient interviews, data extraction from the same patients' general practice records.
2. Organisational case studies: key informant interviews, grey managerial documents, secondary administrative data, official websites.

Data validity was assessed by checking patient interviews against general practice records, triangulation (case studies) and comparison with other published studies. Data were synthesised using three nested framework analyses at cross-site level (England) and one at cross-country level. The original analytic framework and hypothesis were then reviewed in the light of the empirical findings.

Results

Starting from data about patients' experiences of care, we found that certain care co-ordination mechanisms were present in both the integrated organisations and the care networks we studied:

1. consultation model of care co-ordination.
2. interdisciplinary care teams (often several in parallel).
3. 'virtual ward' or 'hospital at home' models of care, although often with patchy coverage.
4. integrated electronic patient records to which different professions have read-write access (with varying degrees of access and duplication).
5. colocated services.

The main obstacles to care co-ordination within the integrated organisations were:

1. professional silos, with rivalries between occupational groups
2. discrepant information technology systems for different divisions (care groups) within one organisation
3. non-medical case management less developed in the integrated organisations we studied than within the networks.

Obstacles 1 and 2 were also present in care networks.

Within the care networks we studied, the following additional barriers to care co-ordination were identified:

1. information flows that were incomplete and often laborious to maintain
2. conflict between the referral, financial and information flows required by care pathways and those required by the consultation model of care co-ordination, particularly when patients were discharged from hospital
3. means tests for services, which created bottlenecks that obstructed care co-ordination
4. capacity mismatches between successive providers in the care process
5. weak or absent interorganisational links
6. mismatched financial incentives and managerial targets across organisations
7. the separate location of services whose collaboration was required for complex care.

Organisationally integrating services within one organisation aided care co-ordination by:

1. creating line-managerial accountability for care co-ordination and continuity
2. making patient transfer between professions, specialities, in-patient and domiciliary care, and between health and social care usually more easy, flexible and swift than equivalent referrals across interorganisational boundaries
3. colocating services by default (although the 'location' might be a locality with staff working across it), whereas in a network of independent organisations separate location was the default
4. removing information governance differences between organisations
5. making it harder for subunits or services to secede (in a network organisations can unilaterally decide to join or leave)
6. having one workforce provide both clinic-based [e.g. general practitioner (GP) surgery] and domiciliary services, which appeared to facilitate flexible, cross-sectional and longitudinal continuity of care
7. avoiding the administrative overheads of indirect referral routes and care network management in addition to management costs at provider level
8. aligning overall goals and external incentives across all services within the integrated provider
9. pooling provider income so that decisions about care pathway design within the integrated organisation were not, as in care networks, influenced by considerations of income allocation between organisations.

On balance, therefore, an integrated organisation appeared more favourable to producing continuities of care than a care network. With adjustments of detail, these findings also apply to the co-ordination of primary care with inpatient care.

For both integrated organisations and care networks, the simplest way, in the short term, to gain access to additional services for their patients was to either colocate or subcontract these services, for which a care network structure was suitable because it was more flexible. For longer-term and larger-scale access, extending an integrated provider organisation had the advantages outlined above.

Ownership differences in this sample of providers affected the range of services to which patients had direct access, primary care doctors' managerial responsibilities (relevant to care co-ordination because of its impact on GP workload) and the scope for medical innovation. Privately owned and/or managed primary care providers appeared to have greater informational continuity of care internally, but less externally (to patients and hospitals). Professional partnerships gave GPs flexibility to develop their own interests or specialisations. In Sweden, the integrated, publicly owned polyclinics gave patients direct access to a wider range of services than the English general practices did. Except for the clinic heads, Swedish polyclinic doctors had no equivalent to the practice-management workload of English partner GPs.

We found little difference between integrated organisations and care networks in terms of managerial discretion and performance. A larger difference was between NHS and Swedish primary care organisations, whose management in many respects resembled NHS practice some years earlier. Senior manager advocacy was a precondition for activities both to establish care networks and to amalgamate previously separate services. Clinician advocates were equally important for introducing and promoting projects and for maintaining close working relationships at senior medical management levels between organisations.

Conclusions

Because of the small scale and scope of general practice services, patients who require round-the-clock or multiple services have to be referred immediately from their general practice to other providers. Care network co-ordinating bodies exist partly as a workaround for the ensuing problems of care co-ordination. Our evidence (frequently evidence of its absence) suggests that a care plan, shared among providers and with the patient, is an important means of co-ordinating a patient's care and strengthening its continuity. Recording and sharing a care plan, however, requires information systems that capture this (and the supporting clinical) information and allow the relevant professionals to share in access to it. The balance of evidence suggested that an integrated organisation containing a wide range of services (above all, primary medical care) is more likely to favour the development of care co-ordination, and therefore the continuities of care, than a system of care networks. The structural options for organisationally integrated primary care providers include:

1. publicly owned polyclinics on (e.g.) the Swedish model
2. corporate primary care providers
3. polyclinics operated by a co-operative, clinician-owned or other 'third-sector' organisation
4. professional partnerships of larger scale and scope than is now usual in the NHS.

Any of the above could be managed, and where applicable owned, by doctors, nurses, other clinicians or a mixture.

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Chapter 1 The policy context

Nearly one-sixth of NHS patients have multiple morbidities.¹ They usually need more extensive and varied health-care inputs than one clinician can provide, besides 'social' care, informal support and sometimes secondary care, all adjusting to changes in their circumstances or health. Co-ordinating all of these elements of care is an enduring problem for the NHS, as yet imperfectly solved.² Survey data from 2002–3 showed that in the preceding 2 years, 49% of a sample of patients with serious health problems had to tell the same history to multiple health professionals, 23% of test results were not available in time for appointments, 13% of patients had duplicate tests or procedures and 19% received conflicting information from different health workers. These problems were especially prevalent for patients seeing multiple doctors. Furthermore, it appears likely that under-coordination most severely affects the poor and vulnerable,³ especially those with long-term conditions and multiple illnesses such as older patients and patients with both physical and mental health problems.³ Complex care that is sufficiently co-ordinated to avoid such problems is often called 'integrated' care, meaning 'integrated at the patient or clinical level'.⁴ It is more effective, reduces medical errors or duplicate tests, and increases the likelihood of post-hospital follow-up care and patient satisfaction.^{2,5}

This research examines the ways in which care co-ordination at the *clinical* level might be promoted by *organisational* integration, that is, a unified organisational structure to co-ordinate and provide the different services comprising complex care.

A tripartite NHS

English health policy has grappled with this issue since 1920. The Dawson Report recommended building primary health centres, in which:

*The domiciliary services of a given district [...] services of curative and preventive medicine [are] to be conducted by the general practitioners of that district, in conjunction with an efficient nursing service and with the aid of visiting consultants and specialists.*⁶

'Domiciliary services' were 'those of the doctor, dentist, pharmacist, nurse, midwife, and health visitor', which ought to be 'suitably correlated' and use 'a uniform system of records of illness'.⁷ Dawson's report ranged wider than this (covering hospitals, physical education and 'recuperative centres') and the government of the day set it aside.

For general practitioners (GPs), a critical part of the 1946 political settlement establishing the NHS was a guarantee that they would not become employees of central or (especially) local government^{7,8} or of any new NHS administration. Community health services (CHS) for immunisation, maternity, community nursing, infectious disease control, school dentistry and young children did, however, remain managed by local government, as did social services. In 1974, CHS were transferred into, and hospital social workers were transferred out of, the NHS. After 1999, primary care trusts (PCTs) combined local networks of independent general practices⁹ with direct PCT management of CHS, until the latter were hived off in 2009. Although official reports since 1956¹⁰ have criticised this 'tripartite division' between general practice, community and hospital services and social services, it persists, producing at times fragmented, duplicated services.¹¹ Correspondingly discrepant managerial practices and regulations impede collaboration,¹² especially between NHS and social services with their different eligibility, copayment coverage and rules.¹³

The problem of how to co-ordinate and maintain the continuity of care provided by multiple organisations, therefore, also persists.¹⁴ In recent years, however, policies to integrate NHS care have become more salient because of the confluence of demography and a set of policies pointing towards person-centred care, including care closer to home, self-care and patient choice of provider.

Care integration

A consequence of the successes of NHS acute care, improved living conditions and lifestyles is an ageing population, an increasing prevalence of multimorbidity and higher numbers of frail older people. Dementia is emblematic of this situation. It has become an increasingly pertinent health issue, to the extent that the Prime Minister has established a special working group to investigate and propose responses. However, it could equally be argued that what makes dementia a policy 'problem', or at least exacerbates it, are the insufficiencies, including fragmentation, of services caring for people with dementia.

The policy of integrating primary care so as to reduce the demand for hospital beds first appeared as a concomitant of transferring patients out of large mental hospitals into community care. Twenty years later, NHS acute hospitals also faced increasing pressures, if not to reduce, then to contain the growth of, demand for acute hospital services. Waiting times for hospital admissions had been a salient health issue since the 1950s and were becoming more so. Unplanned hospital admissions of frail elderly people were a growing part of a hospital's workload,^{15,16} as were delayed discharges from hospital.¹⁷ Patients less satisfied with access to their general practice appeared to be more likely to use emergency departments (EDs).¹⁷ NHS policy came to assume that more integrated care might address all of these problems, reducing the numbers of unplanned admissions and reducing the length of hospital stays generally.¹⁷

Fiscal stringency

After the 2008 banking crash, reducing hospital bed use was bound to be a pillar of fiscal control in the NHS, where 67.5% of costs arise from hospital care.¹⁸ Cuts to local government expenditure fell heavily on social services, but that constrained hospitals' ability to reduce lengths of stay. In response, it was proposed that £1.9B of NHS budgets be transferred to joint local authority and NHS control; however, this 'Better Care Fund' has (in mid-2015) not yet been created.

Provider diversification

Most general practices are professional partnerships, jointly owned by some or all of the GPs working in them and employing nurses and other staff. Since 1997 the policy of provider diversification has extended into NHS primary care, leading to the introduction of:¹⁹

- new general practice contracts [Personal Medical Services, 'New' General Medical Services, Alternative Provider Medical Services (APMS)]
- nurse- and allied health professional (AHP)-led general practices
- extending GP co-operatives to provide certain diurnal services
- commercial general medical services
- case management, both corporately provided and via the Community Matron programme
- social enterprises, whether independently founded or former NHS or local authority services
- PCT-owned and directly managed general practices
- GPs with special interests (GPSIs)
- walk-in health centres.

Increasing technical, and therefore occupational, specialisation within primary care also increased the number and variety of primary care providers. From 2009, PCTs were forbidden to provide services. Some followed the Welsh example of creating vertically integrated NHS trusts that provided both acute health services and CHS.⁹ Both technical specialisation²⁰ and providers' increasing organisational diversity exacerbate the difficulty of co-ordinating care provision across multiple providers, fragment organisational responsibilities and increase the scope for service duplication.²¹

General practitioners as commissioner-co-ordinators

Since the GP fundholding scheme (1991), NHS policy has increasingly made GPs responsible for care co-ordination, a dual trajectory of giving GPs budgets for other primary care services and most hospital services and of making GPs more openly accountable to NHS management for how they use these powers. GP fundholding implemented both of these elements at individual GP and at practice level.

The subsequent evolution of PCTs made GPs collectively responsible, with others, for commissioning most secondary services and, later, CHS. After 2010, Clinical Commissioning Groups (CCGs), of which all general practices were members, were to:

[. . .] bring together responsibility for clinical decisions and for the financial consequences of these decisions [. . .] reinforce the crucial role that GPs already play in committing NHS resources [. . .] increase efficiency, by enabling GPs to strip out activities that do not have appreciable benefits.²²

The 'activities' that GPs would review explicitly included hospital services for which CHS or other forms of primary care might be substituted. In doing all this, CCGs were also to increase the integration of care and give patients a bigger role in (and more responsibility for) selecting and co-ordinating their own care.

Experiments, initiatives, pilots and mandates

From the late 1990s, policy-makers extended their 'reforming' or 'modernising' attentions to primary care 'integration', introducing diverse initiatives, pilot schemes and mandates (Box 1). Although a few of them did attempt to organisationally integrate GPs or general practices with other services, most nuanced the tripartite structure and promoted care co-ordination across the (adjusted) boundaries within it. The policy advantage of framing 'integration' as interorganisational co-ordination or collaboration was that it challenged neither the tripartite structure nor the structural changes introduced for other policy reasons (e.g. marketisation).^{23,24}

Colocation

A physical rather than an organisational remedy was to colocate services. After Dawson's report, the next main innovation (1935) was the Pioneer Health Centre at Peckham. This colocated preventative activities (physical exercise, swimming pool, games, workshops), a day nursery, cafeteria, laboratory, general practice and (after 1946) an infants' school together in a purpose-built building. It was closed in 1950, partly because it offered more services than ordinary general practices and, therefore, required patient copayments.

BOX 1 Care integration policies, in ascending order of organisational integration^{19,25–36}

- Colocation
 - health centres
 - 'polysystems' (London).
- Care networks
 - multiagency teams (for older people, mental health, assertive outreach, crisis intervention)
 - virtual wards ('hospital-at-home', 'acute care at home', shared care, 'Closer to Home' schemes)
 - disease management programmes
 - case management
 - GP federations
 - integrated care pilots.
- Repositioning of organisational boundaries (England, Northern Ireland).
- Organisational integration
 - care trusts (when unified management)
 - corporate or NHS-owned general practices.
- Combined CHS and acute providers (vertical integration).

From the 1950s the Ministry of Health supported the construction of health centres in which to collocate general practices with CHS, dental services and hearing services. Although many were built, they remain far from universal. Despite the Cumberlege Report's³⁷ advocacy of area-based community nursing teams, the collocation, or at least attaching, of CHS staff to general practices became widespread over subsequent decades. Less often, social workers were also colocated to general practices, and in a few areas social care teams came under joint NHS and local government management.³⁸

Stronger co-ordination

Our Health, Our Care, Our Say envisaged substantial expansion of community-based services, including 'expanding the provision of community nursing services to support people at home',³⁹ a key element in the Darzi Report.⁴⁰ The Care Closer to Home initiative (2008) contained no one blueprint for such care but envisaged that it would be system-wide and delivered by enhancing the local workforce, working in partnerships with patients and communities, and investing in better community facilities, stronger CHS and GP-led health centres or 'polyclinics'.

Darzi⁴¹ argued that collocating GPs with CHS and social services [or, failing that, using information technology (IT) to link services] would promote service co-ordination:

*Integrating care is also a key driver of personalisation because [...] there are likely to be fewer appointments on a typical pathway, greater familiarity between patient and staff, better information for the patient, and a more 'seamless' experience for the patient.*⁴¹

The *Next Stage* review (2007) promised the creation of 150 'GP-led health centres', open to patients not registered with GPs (which also addressed the finding that, on the basis of Allocation of Resources to English Areas-weighted populations, deprived populations were seriously underdoctored). These centres would have new buildings, free-standing or near an ED, providing diagnostic services, social advisers, consultants, physiotherapists and one or more general practices, serving a population of 50,000.⁴² To some observers this sounded 'like a GP surgery bolted on to an independent sector treatment centre'.⁴³ The proposal to offer APMS contracts to providers running these centres led many people, including the British Medical Association (BMA), to perceive, and hence oppose, the plan as extending corporate provision of NHS-funded primary care.^{42,43}

Although the government was quick to announce proposals to develop 'polyclinics' across the country,⁴³ the concept remained vague, with no specific blueprint beyond Darzi's initial vision. Developments in practice were more limited and ill defined.⁴² Various developments that did not encompass all the key 'Darzi' characteristics were labelled 'polyclinics', or, in London, 'polysystems'. Some were more like walk-in centres. Few managed to achieve the kind of integrated care 'one-stop shop' that early articulations of the polyclinic model envisaged.⁴⁴⁻⁴⁶ They proved expensive and many attracted only few patients, giving poor value for money.⁴⁷ In London, however, the number of walk-in patients far exceeded expectations, although without reducing pressure elsewhere in the system.⁴⁸

London polysystems

NHS London took the Darzi centre idea a step further. *A Framework for Action*⁴⁹ set out plans for between five and 10 'polyclinics' to be established. The favoured option was locality-based 'polysystems', either physically colocated in a hub building or a 'virtual polyclinic', a care network of existing service providers and locations, with the emphasis on developing primary and community services. To general practice, pharmacy and some diagnostic services traditionally carried out in hospitals, *A Framework for London* added dentistry, physiotherapy, family planning and mental health services, non-NHS services such as social care, voluntary sector and other care providers, and newly created services to promote health and well-being. Darzi argued that London was suited to such concentrations of services because of its dense public transport network. However, the BMA criticised the imposition of the 'super surgery',⁵⁰ challenged the assumption that polysystems would reduce ED attendances and questioned the lack of detail on costs and the implications for hospital survival.⁵¹

A large-scale evaluation of London polysystems⁴⁸ was commissioned, but remains unpublished. Its interviewees equated service with system integration, and both with multiple colocated services. The interviewees considered linking up services with primary care to provide improved patient pathways, an important factor for enhancing the quality of services. Commissioners aimed at developing a 'one-stop shop' offering a comprehensive range of services for the management of long-term conditions and making it easier for patients to obtain a GP appointment. Enabling GPs to obtain diagnostic and specialist services within the community would reduce ED attendances. Fewer than 10 polysystems actually appeared in London, many built on existing developments⁴⁸ and more limited than originally envisaged;⁴⁴ for example, developing single community-based services [for chronic obstructive pulmonary disease (COPD) or back pain]; a colocated GP and walk-in centre with some outpatient consultations; and a new general practice in a hospital ED.

It proved difficult to change GP referral patterns, leading to the underutilisation of community-based services, many of which were small-scale anyway. Community service developments demonstrated improvements in access, particularly geographical access, across a number of sites, but moving hospital services into the community resulted in the duplication and disconnection of services. There were also examples of colocated services related to the same care pathway still working in silos. Only limited numbers of patients used multiple services on the same day. Some GPs were concerned that colocating services had the potential to confuse patients for different services and to create inequities in treatment. Interviews with other staff also suggested that institutional and organisational barriers between different service providers prevented patients from using colocated services on the same day. Furthermore, patients were disappointed that the 'polyclinics' did not offer a comprehensive range of out-of-hospital services. Commissioners lacked guidelines and levers for creating integrated hubs and 'one-stop shops'. Despite using various mechanisms to encourage integration between hubs (e.g. governance arrangements and policies, regular meetings with all providers), the commissioners interviewed for the evaluation considered it unlikely that hubs would be able to offer a truly integrated service in the near future. Most sites identified a variety of logistical, IT and clinical administrative barriers to fuller integration.

However, there were some successes. In one borough a new service was developed with consultant input and clearer patient pathways. It worked in partnership with a private organisation and other selected general practices across the borough to improve quality of care through mapping performance and facilitating co-ordination. Colocating services in the hubs did enable small-scale synergies to be identified. This facilitated more flexible delivery of care in hubs that had sufficient capacity and diagnostic services, encouraging collaboration and partnerships between different services and professionals. Examples included providers sharing clinical and support staff; nurses sharing expertise; informal clinical liaison; streamlining diagnostic and other cross-referrals; holding joint clinics; and better use of space. Colocation of services on one site provided opportunities for staff in one centre to direct patients between the available services, although barriers to capitalising on the opportunity included organisational 'silos' (physical separation, separate funding), organisational restructuring (which made providers inward-looking and hence less collaborative), and different IT systems. Although patients liked the option of accessing many services on the same site, few actually used more than one during each visit.

Integrated care pilots: care networks

Reflecting the tripartite NHS structure, general practice-centred and CHS-centred care networks have both developed, including the polysystems described above. The Integrated Care Pilot Scheme (2008) supported the formation of 16 care networks, coalitions of health-care providers who constructed care pathways across organisational boundaries,⁵² in ascending size from case management schemes to interorganisational care teams⁵³ to care hubs, federations of general practices and NHS–local authority 'partnerships'. Case management was often embedded in these networks, and indeed was the focus of six of them.⁵⁴ Since 2010, NHS policy has encouraged the development of federations of general medical practices that share certain other primary care services such as GPSs, diagnostics, CHS and mental health services; and of hubs mediating referrals from 'federated', usually smaller, general practices to (other) NHS, social care or third-sector providers. For example, in one locality in Plymouth, social workers and long-term

condition managers work as one team with a cluster of practices. The 'Virtual Ward' model is more vertically oriented, with (e.g.) GPs, CHS, social services and hospital consultants providing more acute care at patients' homes than patients would usually receive there.

High-level partnerships between NHS planning (later, commissioning) bodies and local government have existed since the 1970s, originally for transferring patients from long-stay mental hospitals into community care. Later, 'section 75' (§75) agreements allowed the pooling of NHS and 'health-related' local authority budgets under common management. Nowadays, Health and Well-Being Boards (H&WBBs) undertake intersectoral health promotion and foster interorganisational care co-ordination,^{13,23} particularly for frail older people. Interorganisational co-ordination often appears strongest at the top managerial level and more ad hoc at an operational level.⁵⁵ However, there are exceptions. Care trusts come closer to organisational integration. In Torbay, managerial structures and budgets for CHS and social care were pooled below top management level, but general practices remained separate and were linked to other providers by care networks. The Think Local Act Personal scheme is piloting integrated health and social care personal budgets.

A bipartite system

Northern Ireland has a bipartite rather than a tripartite system. Social and health services are combined within NHS trusts. A 'programme of care' approach, with unified budgets, cuts across the division between health and social care. Most managerial posts are open to all professions.⁵⁶ The integrative effects (e.g. removal of organisational boundaries and conflicts, weaker professional demarcations, information sharing) appear stronger at managerial level (e.g. shared policies, provision of specialist and outreach services, staff location) than at clinical level (e.g. assessment, referral and screening practice).⁵⁷ Nevertheless, 'cultural' differences inherited from the constituent services, such as the dominance of health interests, persisted for many years.⁵⁶ General practices remain separate organisations.

Internationalisation of the integrated care agenda

Many other countries have ageing populations with multiple chronic diseases, a hospital-based care system, insufficient community care services, fragmented health and social care providers who do not always co-operate, and problems of rurality.⁵⁸ Department of Health interest in polyclinics and care closer to home was stimulated partly by knowledge of organisations in mainland Europe that enhance care co-ordination and of Kaiser Permanente in the USA.³⁹ Studies of developments aimed at integrating rehabilitative care come mostly from Australia, Belgium, Canada, the Netherlands, Norway, Sweden, the UK and the USA.¹²

In parts of Europe, independent medical practices or (more often than in the NHS) single-handed doctors provide primary medical care. Despite having different policy conceptions of 'integrated care', practical projects in these countries (above all the UK, the Netherlands, Spain and Italy) to improve care co-ordination have been quite convergent, focusing on the horizontal co-ordination of primary care through care networks, care co-ordination tools, case management, joint working and decentralising and/or pooling of budgets.⁵⁸ These activities aim at linking independent general practices to each other and to community nursing and other non-medical services. For instance, in 1999 the Italian National Health Service introduced policies to reinforce group practice and promote co-ordination between primary care physicians and local government services such as social care, home care, health education and environmental health. Primary care doctors were given economic incentives to adopt *Medicina in associazione* (3–10 primary care doctors remain in separate practices but share clinical experiences, adopt guidelines and organise workshops to assess quality and prescribing appropriateness), *Medicina in rete* (networked practices, where additionally primary care doctors share a standard electronic patient record system) or *Medicina di gruppo* (where 3–8 primary care doctors form a group practice with a single electronic patient record system, and may also provide primary care to patients who do not belong to their catchment area).⁵⁹ Primary care centres have existed in Spain since 1981 for the purpose of colocating primary care doctors, nurses, social workers, dentists and physiotherapists. The experimental *Castelldefels Agents de Salut d'Atenció Primària* (CASAP) Centre (Barcelona) gives primary care doctors direct access to

hospital diagnostic services. Reception clerks triage patients to a primary care doctor or nurse practitioner (NP) by algorithm, based solely on patients' own description of their symptoms (clerks do not diagnose).

German efforts to improve care co-ordination have concentrated on integrated care schemes (*Integrierte Versorgung*), in part reconstituting models developed in the Deutsche Demokratische Republik (DDR; the former East Germany) but abolished on reunification:

[DDR] had for instance disease management programmes; they had this for diabetics [...] specific programmes for particular chronic diseases [...] And now they [social health insurers] are trying to rebuild this with a lot of money, rebuild disease management programmes for decades. And these are also contractual – single contract disease management programmes.

Manager, German Association of Social Health Insurers

One obstacle causing the number of schemes to decrease has been the cost and difficulty, within a tariff-based payment system, of annually negotiating non-standard contracts across networks of multiple providers.⁶⁰ The social health insurance system that funds patients' long-term care (*Pflegekrankenversicherung*) is, furthermore, separate from the systems for paying (other) health and social care providers (although it is about to be 'renovated'). In the Netherlands, where health care is also purchased mostly on a tariff system, experiments began in 2013 with fixed-sum contracts for whole-population care programmes for non-hospital care of diabetes, funded by aggregating diagnostic-related-group (DRG)- like tariff payments into block payments for a diabetes care pathway. Similarly, a care network for Parkinson's disease patients consists of a network ('virtual hospital') of recognised providers (GPs, nurses, physiotherapists, etc.) whose network membership depends on them providing a quality of care satisfactory to the network co-ordinators. Patients can access the network online and select which professional(s) they will ask to care for them.

Similar conditions, integration problems and policies also appear in Canada and, with their NHS-like health systems, Australia and New Zealand. The services intégrés pour les personnes âgées fragiles (SIPA: integrated services for frail elders) model, and in a different way the Programme of Research to Integrate the Services for the Maintenance of Autonomy (PRISMA) project, in Canada promoted multidisciplinary teams (MDTs) (with pooled funding and integrated information systems) to case manage older people, using clinical protocols, intensive home care and rapid-response teams. Care pathways were standardised to have a single point of entry, common assessment instruments, clinical charts and service plans.⁶¹ As in Germany, highly commodified⁶² provider payment systems have obstructed care co-ordination in Australia. The Medicare Benefits Schedule (MBS) uses a tightly controlled fee-for-service system to pay general practices and private allied health services, making it difficult to substitute providers (e.g. to extend the roles of practice nurses or physician assistants). Creating new items of payment to accommodate diverse patient needs complicates the MBS further while diluting its incentive effects.⁶³ Fragmented sources of primary care funding and the prevalence of single-handed GPs further obstruct care co-ordination.⁶⁴

Returning to Europe, polyclinics are a common way of integrating primary medical care, community health and sometimes social services within one organisation, employing salaried doctors on the same basis as other professionals. Various governance structures have been used (*Table 1*).

TABLE 1 Integrated primary care organisations: governance options^{25,26,30}

Governance structure	Examples
Corporate bureaucracy	Private primary medical care firms (England)
Public bureaucracy	Polyclinics (Sweden, Finland), primary care clinics (Portugal), Veterans Administration (USA)
Social enterprise	Kaiser Permanente (USA)
Professional partnership	General practices (UK, Australia, New Zealand)
Democracy	Group Health (USA), out-of-hours co-operatives (UK)

According to country, polyclinics may be operated by municipalities (e.g. Sweden, Finland, Catalonia, former Yugoslavia⁶⁵), health ministry (Portugal), regional government (Italy), employers (Russia, Germany) or hospitals (Russia).⁶⁶ Amalgamated primary care providers have been used to co-ordinate primary medical care 'horizontally' with (other) CHS in Italy and Sweden, and, in a few health systems, health-related services such as social care (Italy, Poland formerly), intermediate care, residential care and even veterinary care (because of its relevance to food production). Polyclinics were widespread in former Soviet bloc countries, where the term covered horizontally integrated primary care providers, vertically integrated providers (hospital with attached outpatient and/or primary care clinics) and workplace medical services oriented towards occupational health, but often also open to the employee's family. In many countries polyclinics were rapidly dismantled for being symbolic of the Soviet system,⁶⁷ a step that some policy-makers now regard as precipitate. In Germany, polyclinic-like organisations have been reinstated in a few areas (e.g. Berlin) under a new name (*Medizinischeversorgungszentrum*: medical care centre), although these 'lighthouse' projects remain exceptional.

Of such systems, Sweden has the closest parallels to the NHS in terms of level of technical capacity, health-system funding and political culture.^{68,69} *Vårdcentral* primary health-care centres (PHCCs) are hierarchical governance structures where municipally employed primary care doctors, nurses and therapists are managed in one unit and subdivided into MDTs. They are also typically responsible for population-oriented public health activities (e.g. maternity and well-baby clinics, vaccinations) and their main activity is providing primary care services. *Chapter 10* gives fuller details of these polyclinics and their variants.

In addition, some health systems vertically integrate primary, secondary and tertiary care within single organisations, for example some Russian hospitals, Kaiser Permanente, and integrated Foundation Trusts in the NHS. In such fragmented health systems as in the USA, integration of care has naturally been a salient question. Given also the high cost of US health care, attention has focused more (than in Europe) on the vertical integration of care; that is, developing primary care systems to reduce the use of hospital services. It is also part of the rationale for the recent US health insurance reforms. This focus has also made Kaiser Permanente, with its organisational integration of primary and secondary care services, attract policy-makers' attention in the UK.⁷⁰⁻⁷²

What research has so far contributed to altering policy and practice

As the next chapter shows, there is a 'babel'⁷³ of research on health-care integration. Such research has concentrated mainly on evaluating specific techniques and – in many countries – on particular local initiatives aimed at increasing the integration of care. Its influence on policy can be seen, in the NHS, on the formation of 'vertical' care networks linking general practices and hospitals with a view to managing hospital referrals and discharges more efficiently. Where research has had less policy influence – partly because not as much research has been available – is on the question of how micro-level management techniques and projects interact with each other, and with the organisational structures through which these techniques and projects are implemented; that is, the question of what approaches to integrating care work under what conditions, for whom, and whether or not the health gains are worth the transaction costs. Nevertheless, think tanks and policy-makers persist in demanding more integrated primary care. We next consider what existing evidence does tell us about how organisational structures might influence the co-ordination of care.

Chapter 2 Care co-ordination and integration: process and structures

Overall, research and policy discussions about care integration are a conceptual mess, lacking standard categories, concepts or terminology.^{23,74,75} 'Persuasive definitions'⁷⁶ often take the place of taxonomy. In this chapter we designate which concepts of 'integration', 'co-ordination' and 'collaboration' this study will use. We outline a realist synthesis⁷⁷ (see *Co-ordination: the production of continuity*) of existing research findings about which mechanisms, and under which organisational conditions ('contexts'), appear to promote (or obstruct) to policy outcomes of care 'integration', 'co-ordination' and 'continuity', so defined. In this way, we derive hypotheses amendable to empirical testing.

We follow the World Health Organization (WHO) in defining integrated care as 'bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion [. . .] to improve services in relation to access, quality, user satisfaction and efficiency'⁷⁸ – a 'patient-centred' approach.⁷⁹

Continuities of care

Because continuity of care has many dimensions, it makes more sense to speak of 'continuities' of care (plural). Combining and condensing two earlier schemas,⁸⁰⁻⁸² we differentiate six main continuities (or discontinuities) of care at the clinical level:

1. *Cross-sectional continuity* (synonyms: 'clinical', 'comprehensive', 'holistic', 'management', 'therapeutic continuity'^{34,82-85}) denotes managing a patient's complex health conditions as a totality in the light of how they, and the corresponding interventions and care, interact, so as to produce a single, consistent care process to meet all of the patient's health-care needs.⁸⁶ This is critical when more than one provider is needed at a time.
2. *Longitudinal continuity*, which is planned contact and treatment being maintained when providers change (e.g. shift changes, staff turnover, patient transfers), or maintaining contact with the same provider, measured by examining the rates of overall contact or gaps in contact^{87,88} or the proportion of contacts with the same provider, or assessed subjectively from patients' own accounts.⁸⁹
3. *Flexible continuity* ('developmental' continuity, sometimes⁹⁰ subsumed under 'management' continuity) refers to care responding to changes in the patient's circumstances⁸⁰ and hence somebody reviewing these circumstances and changing the care plan accordingly.
4. *Continuity of access* refers to how complete and accessible the range of available services is, compared with the patient's health-care needs.^{84,89,91}
5. *Informational continuity* (or 'continuity of communication') means that the patient's care plan is decided on the basis of all the available relevant information about the patient's history, current condition, circumstances and care needs.^{82,83,85,90} This requires an information system that supplies clinical teams with feedback and decision support (e.g. access to or implementations of guidelines).⁹²
6. *Relational (or 'personal') continuity*, while theoretically possible within one encounter (and also related to cross-sectional continuity), relational continuity essentially means ongoing contact with the same individuals (care co-ordinator, informal carers, clinicians)^{82,85,90,93} during the care process, so that these carers come to know the patient's medical history and personal circumstances in the round,^{85,94} and, crucially, build up relationships of trust.⁹⁵⁻⁹⁷ Then the patient is more likely to engage with each clinician, to disclose any psychosocial problems⁹⁸ and to adhere to an agreed treatment plan.^{99,100} This particularly appears to be the case for patients with more chronic or serious conditions, psychological or social problems.^{74,94,101-104}

These continuities improve the outcomes of care and its safety^{3,35,80,105} (although Gray *et al.* cite counter-examples¹⁰⁶); patient satisfaction,^{80,83,87,90,91,95,101–103,107–110} adherence^{83,99,100,111,112} and capacity for self-management; and the efficiency of service provision.^{105,111–114} The balance of evidence suggests that they may reduce the unscheduled use of secondary care.^{105,115} It appears reasonable to assume, although there is little corroborating evidence, that a patient's enduring contact with a single provider leads to stronger relationships, better information transfer and more consistent management;⁸² and to more person-centred care (i.e. care focused on enabling the patient to achieve, as far as feasible, the life goals and activities of daily life to which they attach the most importance¹¹⁶).

The patient: producing and experiencing continuity of care

Patients as care co-ordinators

Most patients expect to have a role in co-ordinating their own care⁹⁰ and, indeed, must when health professionals fail to co-ordinate it for them.⁵ (See *Appendix 1*, which elaborates some of these points.) Wagner's 'pyramid'¹¹⁷ of care implies that patients in any case provide much of the care for themselves. Those who do are less likely to consult a GP.^{118,119} An important way in which patients co-ordinate their own care is by mobilising their informal social support networks, differentiating between friends, relatives and others from whom they obtain different kinds and amounts of support.^{120,121} Formal services can also help patients self-manage their care (e.g. by helping people with psychiatric problems manage their financial affairs¹²²). Personal budgets supplement the patient's resources, strengthening the patient's role as care co-ordinator. An evaluation of the personal budget schemes for social care found that, on balance, clients thought that having a personal budget had increased their control over what services they received, and to that extent their quality of life. These responses were most prevalent among clients with a physical and/or mental disability.¹²³

However, there are practical limits to patients' self-co-ordination of their own care. One is how far patients can or will travel to receive care,¹²⁴ especially older people who have limited mobility and rely on public transport. Caregiver burden appears to be a predictor of the institutionalisation of frail older people, particularly those with dementia.¹²⁵ For more dependent older patients, care transitions (often, into a nursing home) may be initiated by their informal carer, especially when the carer's skills are ill matched to the patient's needs. A US study found that male informal carers (especially husbands and sons) were more likely than female carers to request such a transition, as were informal carers of the opposite sex to that of the patient.¹²⁶ The patients most needing co-ordinated care are often those whose multimorbidity¹ and multiple medication make it hardest for them to co-ordinate their own care⁵ and for whom hospital admission is less discretionary.¹²⁷ The severity of the condition and the level of distress predict help-seeking for mental health problems.¹²⁸ Self-management programmes also have, in some contexts, high dropout and refusal rates (10% and 51%, respectively, in a Spanish study).¹²⁹ Cross-sectional, longitudinal and relational continuities of care are likely to break down when users are highly mobile, even within a small locality, for instance for patients with serious mental illnesses.^{130,131} When these practical limits are reached, patients often seek help (an extensive body of research describes under what circumstances they do or do not do so). The task of co-ordinating their care then passes largely to their health-care providers.

Co-ordination: the production of continuity

Processes and structures for care co-ordination

In most health systems, the process of providing complex care consists of the following sequence:

1. A person co-ordinates their own care.
2. The person seeks help from formal services.
3. The patient attends a first responder, typically a primary care doctor (but alternatively the ambulance service, hospital ED, etc.).
4. Where needed, the patient is transferred to further providers (CHS, psychiatric care, hospital, etc., as relevant).
5. These 'second-responder' providers then provide and co-ordinate care.

This is a simplification. Further transfers to yet more providers may follow stage 5, including feedback loops returning the patient to an earlier provider. Further iterations of steps 3, 4 and 5 may occur (e.g. the 'revolving door' between outpatient, inpatient and community care of mental health problems). A patient or health worker may initiate, even duplicate, several of the above processes at once. The sequence may be truncated for some reason (e.g. the patient withdraws consent).

The ways in which health-care organisations conduct steps 2 to 5 produce the patient's experience of continuities or discontinuities of care. After step 3, each transition is an opportunity for the care process to continue – or to be deflected or disrupted, endangering its continuity and tending to increase risk, adverse events and costs.³³ The increasing technical, and hence occupational, specialisation of health-care providers, and policies that promote more diverse ownership of providers, make it increasingly likely that patient episodes will be distributed across multiple professions and/or organisations, with correspondingly more transfers between them.⁵ Studies of these processes (especially experimental studies) have tended to concentrate on chronic disease (cardiovascular disease, diabetes, asthma, COPD, acquired immunodeficiency syndrome/human immunodeficiency virus); mental health, including substance abuse; and care of the elderly¹³² – increasingly prevalent conditions⁹² whose treatment characteristically involves transferring both patients between multiple providers, including social care.

The more transitions an episode of complex care involves, the greater the need for a deliberate attempt to articulate the different carers' interventions into a coherent care process¹³³ and make the patient's transitions between these providers as easy, prompt and non-disruptive as possible.⁸⁰ That is, the need is greater for care co-ordination⁵ as a 'continuity mechanism',⁸⁰ for 'continuity is how patients experience integration of services and coordination'.⁹⁰ Clinical care co-ordination requires the following steps:

1. A care co-ordinator (an individual or team) combines different providers' separate inputs, with a clear division of labour between them, into a coherent care process¹³ that meets the patient's care needs in the round (to produce cross-sectional continuity of care). A care plan documents these points.
2. The care co-ordinator maintains an ongoing relationship with the patient²⁴ (to produce relational continuity).
3. The patient's care plan, which includes social care,^{74,90,134} is shared between the different services involved (to produce cross-sectional continuity at each encounter between patient and provider, and longitudinal continuity over time).
4. The case co-ordinator reviews the patient's circumstances and, if these change, alters the resources or services offered (to produce flexible continuity).
5. The patient has access (often facilitated by the care co-ordinator) to the range of services that they need, with no obstacles to access, missing services or interruptions of services during the period of the care plan (to produce continuity of access).
6. Transfer of information occurs between workers and between organisations and/or shared access to electronic clinical records (to produce informational continuity).

Observing the above features would be evidence of continuity and co-ordination of care.

However, the structures through which health systems undertake care co-ordination are nested. Working 'outwards' or 'upwards' from the patient level, the production of continuity of care typically involves four organisational levels:^{135,136}

1. Patients co-ordinate their own care.
2. Co-ordination within one provider organisation (general practice, community mental health trust, etc.), which may involve a named care co-ordinator.
3. Interorganisational co-ordination through a care network of separate provider organisations;⁵² or 'virtual' integration (as in most NHS 'Integrated' care schemes). Horizontal co-ordination is that of multiple primary care providers, vertical co-ordination that of primary with secondary care.¹³⁶ (We do not equate 'vertical' with 'hierarchical' and 'horizontal' with 'network'.¹²²)
4. The local health system sustains a set of overall governance structures within and through which provider organisations and care networks collaborate, controlled by higher-level bodies.¹³⁷

Evidence is accumulating that care co-ordination depends on the interaction of structures at all these levels.^{92,138,139} 'Coordination structures' have 'consequences for personnel' and these have 'consequences for clients'.³³ For instance, Wagner's well-known model¹¹⁷ views chronic disease management as requiring six 'pillars': community resources and policies, health-care organisation, self-management support, delivery system design, decision support and clinical information systems. Programmes that contain elements of the Wagner Chronic Care model have been shown to be likely to improve clinical outcomes and care processes for both single diseases and multimorbidity.⁹² A systematic review¹⁴⁰ of studies concerning interventions based on the Wagner model found that 32 of the 39 studies reported improvement in at least one process or outcome measure for patients with diabetes. For diabetes, asthma and congestive heart failure care, 18 of the 27 relevant studies reported reduced health service use or reduced costs. Despite methodological problems with some of the studies (many evaluated time-limited special projects rather than typical health-care practice), the evidence suggested that implementing interventions based on the model appeared to support improved health-care outcomes. Evidence of the economic impacts of 'integrated' care is sparse and, overall, inconclusive.¹⁴¹ More studies focus on general practice 'characteristics' (number of doctors, team climate, etc.) than on how such practices are organised.¹⁴² In this research we focus on, and contrast, the intra- and inter-organisational levels of care co-ordination.¹⁴³

First-responder provider organisations

An episode of complex care begins when a patient accesses a 'first-responder' health-care provider where a clinician (typically a primary care doctor or NP^{64,144}) first assesses the patient. In light of this assessment (for many people with complex care needs, a formal risk assessment), this health worker transfers the patient to others, either because the latter have more 'appropriate' expertise,^{23,145} including perhaps in care co-ordination,¹⁴⁶ or because the patient requires more care than one health worker can provide (e.g. round-the-clock care). This act of initiating additional care makes the first clinician the patient's initial care co-ordinator. However, a health worker who sees himself or herself as the care co-ordinator may trigger a conflict when the professional to whom he or she sends the patient sees that as transferring full responsibility for the patient's care to him or her, especially when the two prefer very different treatment methods.¹⁴⁷ Other causes of conflict or delay are that one professional refers 'unsuitable' or 'non-priority' patients to another; different professions or professionals compete for the care co-ordinator role; no one wants to assume overall responsibility for a patient's care; or someone who does not want to is compelled to take such responsibility.¹⁴⁷

Care plans

Care plans are the standard way to assemble and define flexible, individually tailored combinations of services for each patient,²⁴ possibly including elements of self-management,⁶⁴ patient education and planned communication with clients and families (e.g. through joint consultations and reminders).⁶³ As a means of co-ordinating care¹⁴⁸ they exploit the formalisation and standardisation of work processes found in 'ideal-type' bureaucracies, which one would expect to promote longitudinal continuity of care and, when care plans are reviewed, flexible continuity.

Nowadays care plans often involve the application of care guidelines,¹³⁶ which facilitate informal relational co-ordination in hospital settings^{149,150} and so, perhaps, elsewhere. Thus, Swedish polyclinics use specific models of care (e.g. for preventing hospital admissions, disease management, case management, other chronic care and illness prevention models³), clinical indicators and standards, and agreements about what referrals are appropriate. Stepped care protocols, including 'enhanced' (accelerated) referral, can be used to define appropriate referral criteria for specific conditions. A systematic review¹⁵¹ found that such protocols produce clinical benefit in mental health services. However, there are technical limits to formalising and standardising complex care. The course of many non-cancerous diseases,¹⁴⁴ for instance mental-physical multimorbidity,¹⁵² involves clinical complexity that is hard to predict and difficult for protocolised, routinised or pre-planned health-care processes to accommodate.^{12,147} Many of the studies underlying evidence-based guidelines were designed expressly to exclude patients with comorbidities. A perception of receiving 'production-line' treatment may make patients less compliant.¹⁵³

Co-ordination mechanisms within a single organisation

'Organisational integration' means that a single organisation undertakes these activities, rather than separate organisations.¹³⁶ Patients' care is co-ordinated by a unified management structure that applies a single set of objectives when planning, financing and delivering (producing) care.²⁰ Within integrated organisations, three mechanisms for co-ordinating patient care are widespread:

1. the consultation model
2. line management
3. internal interdisciplinary teams.

In practice these mechanisms often coexist, not always comfortably.

The consultation model of care co-ordination¹³³ involves both a '*captant*' profession that focuses on the patient's care as a whole, in the round, and a complementary set of professions that focus on more specific tasks.¹⁴⁷ Typically, the *captant* health worker (classically a GP) transfers or refers patients to other professionals with more 'appropriate' expertise^{23,145} who, having made their contributions, return the patient to him or her. This referral pattern can be visualised as a star-like structure with the *captant* professional at its centre. The *captant* professional acts as care co-ordinator, unless he or she delegates that role, too, to another health worker. Within a hierarchy the most straightforward way to implement the consultation model is to make the *captant* professional line manager of the other professionals. One would expect the consultation model to produce high relational continuity of care with the care co-ordinator and low relational continuity with the *non-captant* professionals. Even within large NHS general practices, it is often possible to maintain a single GP care co-ordinator for most people with long-term conditions, but for individuals who are home bound or struggle to reach the practice and have multiple input from external teams (district nursing, mental health, social care), the GP is less likely to be able to fulfil this role.

Line management in an 'ideal-type' bureaucracy would allocate each patient's care to one health worker or a group of them, and formalise and standardise procedures for hand-offs between care workers,¹⁵⁴ assisting collaboration¹² and care co-ordination. Besides using formal care plans (see p.13), an ideal-type bureaucracy would co-ordinate care by standardising:

1. Information transfer, producing informational continuity^{5,82,135,155,156} by implementing compatible, even shared, information systems (data definitions, IT protocols) across departments and the whole organisation.
2. Procedures for requesting and accepting (authorising) patient transfers between health workers, with uniform criteria defining which transfers are appropriate, so as to establish longitudinal continuity of care. (Evidence-based care pathways are one way to achieve this.)
3. Other working practices relevant to transfers, for example common hours of work.⁸⁹

Within a professional partnership of GPs, the partners stand at the apex of a hierarchy that line manages the non-partners' (employees') work. In these circumstances there is little practical difference between the way the consultation model works within a partnership general practice and conventional line management. However, as practice size increases, multiple GPs tend to become involved in one patient's care.

A sufficient scale of service provision to implement the care plan is also required. For instance, to engage mental health service users and deliver improved mental health outcomes and social inclusion⁸⁸ requires that, say, assertive outreach team staff have sufficient time to build and maintain working relationships with their clients.¹⁵⁷ Corporations and public bureaucracies¹⁵⁴ can exploit the formalisation and standardisation of work processes to routinise, automate and deskill work, using cheaper, more flexible staffing arrangements, and to that extent increase labour productivity. Examples of this tendency include the introduction of call centres,¹⁵⁸⁻¹⁶⁰ telephone-based care management¹⁶⁰ and the development of case-load norms for community matrons.³⁶ A larger organisation (e.g. the bigger US physician practice partnership vs. single-handed practices) is also more likely to have economies of scale permitting the use of, say, expensive diagnostic equipment.¹⁶¹ However, the larger the provider organisation, the more difficult relational continuity might become to maintain.⁷⁵

The greater the range of professions and services contained within an organisation, the greater the flexible and access continuities of care one might expect. In theory, formalisation and standardisation of care plans (see above), information systems (see below) and a clear, explicit division of labour should produce efficient collaboration between specialisms.

In practice, however, health-care providers typically accommodate specialised care by developing an organisational structure¹⁶² in which uniprofessional hierarchies ('semi-detached' professional 'silos'¹⁶³) coexist in parallel, formally linked to each other and to 'general' management only at senior level via 'hybrid' clinical managers.¹⁶⁴ Each profession tends to cultivate the habit of other professions referring to them 'good' patients 'appropriate' to their established ways of working.¹⁴⁷ Certain professions see their role as limited to a determinate part of the care pathway; others see it as overseeing the whole patient journey.¹⁴⁷ In such organisations interprofessional demarcations and rivalries,^{56,165,166} reflecting 'turf wars' over status and resource control,^{33,167} often hinder the creation of common working practices (equated with control from outside the profession). Specialisation may fragment a general practice's 'procedural' organisational memory of how to operate and co-ordinate care interventions.¹⁴⁸ Studies of psychiatric services in France and Sweden found that team members' perception of the psychiatrist's higher status impeded collaboration (they focused on the psychiatrist's views rather than the patient's needs^{122,147}). Doctors especially are reported¹⁶⁸ to resist what they perceive as overmanagement, at times equated with any non-medical management, which may actually reduce doctors' 'citizenship' and 'behavioural commitment'. However, managerial and interprofessional links created for practical operational purposes, and focusing on the health outcomes of collaboration, have the opposite effects.^{151,169} In the USA, health maintenance organisations (HMOs) spread only by diluting the strong management and vertical integration of the likes of Kaiser Permanente.¹⁷⁰ Under the admitting-rights model or where primary medical care is organised on specialty lines (e.g. Germany, France¹⁴⁷), the self-image of the doctor, even in primary care, is more as a specialist expert than as a care co-ordinator. A multiple case study¹⁷¹ reported GPs as being reluctant to relinquish what they saw as their central role in the clinician-patient relationship and wondering if interprofessional working would reduce their autonomy.

Internal interdisciplinary teams can co-ordinate care across professional 'silos' even when the care co-ordinator has no line-management authority over the other professionals¹³⁵ (a 'project team' arrangement, common outside health care^{172,173}). Published studies seldom say whether their findings apply to teams within an organisation, to teams working across organisations or to both. That often has to be inferred from the study setting. Paradoxically, studies of hospital teams may be more relevant to integrated primary care organisations than are studies of teams in fragmented primary care networks.

A recent systematic review²³ describes interdisciplinary teams as a prerequisite for the effective, integrated care of older people. A care team can undertake assessment and care planning, implement disease-specific guidelines and support self-management,⁶⁴ a collective care co-ordinator role.¹⁴⁷ The team may have a nominated co-ordinator who negotiates and agrees care plans with the other team members,¹⁷⁴ for instance at case conferences or the equivalent. The impacts of team care co-ordination appear greatest for patients previously not linked with services, lacking knowledge of their condition and motivation to change their behaviour and lifestyle risk factors, but having some capacity for self-management.⁶⁴

Co-operation between team members depends on what place each occupational group has within the care pathway.¹⁴⁷ Many studies suggest that aligning 'cultures'¹⁷⁵ and team climate is important in influencing how far, and how effectively, the above activities occur. Mechanisms for bridging between professions with different occupational cultures include informal relationships¹⁷⁶⁻¹⁷⁸ and personal affinities among team members.¹⁷⁹ Good-quality information sent to other professionals was reported in a French study¹⁴⁷ to improve relationships between other professionals and the referring doctor. Especially when the team is being set up,¹⁷⁴ it is necessary for its members to commit themselves to shared assumptions about their roles, ways of interaction and common tasks¹²² (which does not require complete convergence of their mental models). Such agreement is more likely in long-established, highly interdependent teams with a small, stable membership.¹⁷⁵ The more varied the services or occupations involved, the harder it is to co-ordinate a team.¹²¹ Scores for satisfaction, continuity of care and access to care are higher in general practices where staff report a better team climate.¹⁸⁰ One would expect co-ordination by a team to produce weak relational continuity but strong cross-sectional and flexible community.

Primary care teams' reported imperfections include lack of ownership of the management of some conditions (e.g. dementia, mental health problems, multiple comorbidities).¹⁸¹ Where the patient's carers remain the same, relational continuity – in effect, the patient himself or herself transmitting information informally – can to a limited extent substitute for weak informational continuity in IT systems.⁸⁰ Team co-ordination may improve patient well-being, but it does not necessarily produce cost savings.⁶⁴

Vertical integration

Vertically integrated 'systems' combine primary with hospital care, for instance when hospitals acquire physician groups,¹⁸² financed by some form of shared budget (e.g. a capitation system). Transaction cost theory predicts that vertical integration reduces uncertainty and 'opportunism' (dishonest transactions), makes information about services transparent, and so reduces transaction (i.e. managerial) costs and sustains a common 'mission'.²⁰ An extensive study²⁴ found that the care co-ordination programmes that were more successful in reducing hospital admissions for older people with chronic conditions involved multidisciplinary assessment of a broad range of patient needs (medical, functional, psychosocial); following the patients up over time (at home, not just at the doctor's premises); health education; supporting patients in making lifestyle changes; and co-ordinating care across different providers.

Having controlled for a 'California effect' (Medicare-financed hospital admissions in that state were half the NHS rate) and population age differences, Ham *et al.*⁷¹ found that for 11 major care groups, Kaiser Permanente (which integrates health insurance, hospitals and ambulatory care doctors) had admission rates and average length of stay of around one-quarter of NHS levels (in 2003).⁷⁰ The researchers attributed these effects to primary care doctors having an interest in keeping Kaiser Permanente solvent; specialists working across hospital and primary care; a lack of incentives to maximise admissions; use of care pathways and specialist hospital discharge staff; and primary care doctors' fast access to diagnostic services. Ham *et al.* also argued that

the existence of competitors to Kaiser Permanente motivated these effects. Recent overviews of research on integrated health systems in the USA together suggest seven characteristics of successful vertically integrated health-care organisations:^{20,33}

1. hierarchical governance or long-term relationships between organisations that approximate to that (e.g. micro-commissioning⁵⁵)
2. 'systemness',²⁰ that is continuity of care and provision by teams, enabling the substitution of less for more costly models of care. This is what Øvretveit *et al.*³³ call 'clinical integration', that is, how well services are co-ordinated between people and sites over time
3. capitation payment, creating incentives for preventative care
4. competing with other providers on quality rather than cost
5. good management and information systems, with 'functional integration' (i.e. support functions such as the management of finance, human resources, IT and planning closely co-ordinated across units)⁸⁶
6. a sufficiently large organisation and population served to ensure long-term stability of the organisation and enable the development of care pathways for common diseases
7. doctors who actively participate in management and are economically linked to their organisation.

Horizontal integration also requires these conditions.

In theory, vertically integrated organisations have an incentive and the means to replace hospital with primary care, a development usually assumed to be cheaper and to improve access, relational, flexible and informational continuities of care, and, therefore, patient satisfaction. Regarding the cost of tests [but not magnetic resonance imaging (MRI) scans] and minor procedures, there is some US evidence to support this assumption.¹⁶¹ Substitution also avoids disruptive transitions between care settings. In England, GPSI dermatology services were more costly than hospital outpatient treatment, but had similar outcomes and better access.¹⁸³ The NHS 'Closer to Home' project was a hospital outreach scheme that supplemented rather than replaced existing services. Patient-reported waiting times, quality of care (although some providers expressed concerns about worse quality), overall satisfaction and access improved compared with existing services; care co-ordination and interpersonal quality of care did not. The new services only treated less complex conditions, although they did this at a lower cost than the standard NHS hospital tariffs.¹⁸⁴ Technical developments (e.g. non-interventional cardiology, development of scanning and diagnostic equipment that could be used in non-hospital settings) aid in these substitutions.¹⁶¹

Transfer between provider organisations: care networks

We present the variants of care networks in ascending order of complexity and formality.

Emergent networks

Emerging from habitual referral or information flows,^{12,52} a care network of interdependent providers^{151,185} co-ordinates health, and often social,¹⁸⁶ care for a defined care group. Some call this 'virtual integration'. At their simplest, care networks may work by nominating 'link workers' as care co-ordinators for individual patients and/or care groups.^{187,188} Through repeated use^{147,188} or prior decision, such arrangements become normalised,^{189,190} even to the point of developing formalised systems for planning and co-ordinating patients' care,¹² requiring 'a sound system of referrals'.¹⁸⁶ A Massachusetts study¹⁹¹ found that larger, care network-affiliated practices are more likely to have the 'structural capabilities' for patient assistance and reminders, a culture of quality, enhanced access to services, and electronic health records (EHRs). A systematic review⁶³ found that the care co-ordination projects with the greatest impact on health outcomes were (in descending order) those addressing relationships between service providers, clinical co-ordination arrangements, and infrastructural support for co-ordination. Those with the greatest impact on patient satisfaction addressed relationships and communication between service providers, and gave 'support' to clinicians and patients. However, fewer than 20% of the studies in that review reported financial gains. Continuity of access in care networks depends on the network involving all the providers

that patients need.¹² The greatest obstacle to care co-ordination is when key providers do not participate in the relevant care networks, which then lack links to other providers.¹⁹² Successful programmes [e.g. SIPA, Integrated Care in Italy, Project for Advocacy, Counselling and Education (PACE), SA HealthPlus] have tended to include geriatricians, primary care doctors or both.²³

The consultation model may operate only within a single organisation, but classically it also extends across organisations. In NHS-like systems, GPs are usually the default care co-ordinator,¹⁹³ this is an important part, the Royal College of General Practitioners (RCGP) says,¹⁹⁴ of what makes GPs 'generalists' and the traditional mode of care co-ordination in general practice. The complementary *non-captant* roles may either be ongoing (e.g. nursing support) or transient (e.g. imaging services). English GPs sometimes delegate to nurses the management of more minor and stable medical conditions.^{195,196}

The consultation model has two limitations. First, it depends heavily on the skills of the *captant* professional, usually a primary care doctor. In some US projects a patient coach¹⁹⁷ has been employed to check that the patient understands and agrees with the proposed course of treatment, and to help in co-ordinating care among the (other) providers involved, including informal carers.⁵ Although patients value relational continuity, over 13% of patients in a study in London and Leicester stated that they had not experienced it in their general practice.⁸⁵ Survey data in 2002 suggested that 38% of a sample of UK patients said that their doctor had not stated the aims of treatment; 67% said that the doctor had not asked about the patient's ideas on treatment and care [although 65% also rated their doctor(s) as 'excellent' for 'Listening carefully to health concerns' and 57% rated their doctor(s) as excellent in diagnosis]; and 75% reported long waiting times for care (which included hospital care).¹⁹⁸ In past decades, GP referral notes to consultants often had meagre clinical content.²⁰ One study suggested that GP interest in care co-ordination tended to trail off once patients had accessed other, specialist providers.¹⁸¹ US studies suggest that the increasing pressure on primary care doctors' time and the complexity of their tasks are practical obstacles to care co-ordination, which requires time between patient appointments,⁵ but that longer (not shorter) contact times for patients with chronic conditions are associated with better quality indicators, greater patient satisfaction and better patient education.^{180,199} Patients often fail to understand the doctor's advice, although checking that they do (which takes time) is associated with improved outcomes for diabetes care.²⁰⁰ Primary care doctors tend naturally to have a clinical culture, and to be less receptive to interventions or strategies for areas that they cannot directly influence (housing, social care, etc.).¹³⁵

One response to these difficulties comes in case management schemes, an updated variant of the consultation model in which other clinicians can replace the primary care doctor as the first point of patient contact with formal care and as care co-ordinator. The case manager is often a primary care nurse^{64,150,201,202} (e.g. NP, 'community matron' or equivalent³⁶), although AHPs, social workers^{203,204} or, when a patient is about to be discharged, a hospital-based 'navigator' can also fulfil the role.²⁰⁵ In theory the case manager regularly reviews the patient's condition (including compliance with treatment); plans, assembles and co-ordinates care inputs from a range of services (a gatekeeper role²⁰⁶); communicates with other professionals (e.g. orally, by sharing records, team meetings);²⁰⁷ and is the patient's first port of call in a crisis. 'Collaborative care' for people with depression and anxiety typically has as the co-ordinator a trained health worker who, where necessary, involves a psychiatrist, other doctors or other clinicians to make a variety of interventions (screening, education, psychotherapy, etc.).²⁰⁷ Care co-ordination might also be undertaken jointly by individuals from different organisations.²⁰⁸ (The cited studies, however, relate to individuals with depression rather than to frail elderly people with multimorbidity.)

In the USA, case management schemes reduced unplanned hospital admissions³¹ and institutional placements of older people.²⁰⁹ English case management schemes did not reduce unplanned hospital admissions²¹⁰ because the UK schemes were applied to patients living in their own home, who are known to make more use of secondary care (ED, outpatient department and inpatients) than patients in residential care²¹¹ (the setting for the Medicare schemes). More effective case finding (also reported in Australia²¹²) might have compensated for lower referral rates among the patients who already participated. However, patients, their families and NHS staff liked the English case management programmes.²⁰⁴ The same applied

to case management patients in Spain. A Spanish home-care service based on nurse-led case management increased access to health-care services and resources, patients' functional ability and levels of satisfaction, while reducing caregiver burden.²¹³ A systematic review of randomised controlled trials for collaborative care²⁰⁷ found that collaborative care produced short-term (up to 24 months), but not longer-lasting, improvements in depression outcomes compared with 'normal care' (typically GP-based, using psychotropic medication) and also improved patient satisfaction, mental quality of life and non-reliance on medications, although it had little impact on physical quality of life. Regular supervision by a case manager was associated with improved outcomes in mental health care, although this effect depended on including large US studies in the systematic review and meta-analysis.²¹⁴

Separate providers naturally tend to work from different sites. Of itself, service collocation creates no new co-ordinating mechanisms and is feasible only when the providers' size and proximity permit.¹²² Nevertheless, one might expect collocation to increase continuity of access and create opportunities for informal information exchange (informational continuity) between professionals and organisations.⁶³ Collocation facilitates,¹⁵¹ but by itself is not sufficient to produce, collaboration across professional boundaries,²¹⁵ including informal links.^{12,80} Collocation can also be used to promote vertical co-ordination, for instance consultant consultations in the community and/or general practice ('outreach').¹³ Conversely, many countries retain an admitting-rights model of hospital medical care, by which the primary care doctor (so to speak) follows the patient into hospital, with concomitantly increased specialisation, possibly loss of the generalist role and, in the USA, close control by the hospital.²⁰ However, joint clinics do not necessarily promote relational continuity of care unless the division of labour between professions is 'carefully attended to'.⁸⁰ Indeed, collocation of general practices was in one instance reported as provoking rivalry and 'bad behaviour' (e.g. removing rivals' notices, misdirecting patients).²¹⁶ As an alternative to collocation, evidence of the efficacy of telephone-based cognitive-behavioural therapy for depression, agoraphobia and obsessive-compulsive disorder is now reported by randomised controlled trials.²¹⁷

Internal MDTs are readily expanded to become interorganisational primary care teams, with the characteristics described above. Cultural continuity plays a major part in sustaining interorganisational teams. Strong norms about the urgency of providing care at the onset of a stroke promoted the development of stronger, more formal co-ordination between ambulance and hospital services in Sweden. The absence of such norms appears to have contributed to the weak clinical co-ordination of post-discharge care found in both the English and the Swedish health systems.⁸⁶

Managed networks

Emergent care networks may not necessarily work well or even form at all. In those cases, 'umbrella organisational structures' are required to create and co-ordinate them,^{23,218} to establish a network identity, policies, structures, care pathways, leadership and resources²¹¹ and to be an arena for meetings between the participants. Such an umbrella can 'solidify the structure for collaboration and support individual professionals working in collaboration to provide care and service for individual patients or clients'.¹²² Care networks become managed (to prevent confusion, we avoid the term 'managed care network'). A network co-ordinating body can develop the sharing of:

1. *Care plans*, which in principle have much the same character, uses and content, with standardised and formalised pro formas, as within integrated providers. In a care network, care planning requires an explicit division of labour,¹⁵¹ defining each provider's accountabilities,²¹⁹ creating referral paths¹³² and harmonising the different providers' working practices. These arrangements have to be negotiated and agreed, possibly even formally, between providers,¹² as no higher manager exists to impose them. The co-ordination mechanisms so established typically include a single, co-ordinated entry point into an agreed care pathway for the whole care group, shared patient registers, a shared assessment and care plan for each patient, and joint consultations and case conferences.
2. *Decision tools*,¹³² for example standardised assessment, triage and care planning instruments,²³ care protocols, periodic reassessments leading to early detection of health problems and consequent interventions,²⁴ and care plans shared across all the providers in the network. Activities such as geriatric

screening and multidisciplinary assessment promote communication between providers²²⁰ (informational continuity). A systematic review¹⁵¹ found that the combination of collaborative care with guideline-directed treatment (a treatment algorithm, stepped care or treatment escalation protocol) and enhanced communication systems improved clinical outcomes in mental health and (on the balance of evidence) reduced costs.

3. *Funding streams*,^{23,132} to align incentives among the network participants;¹⁷⁵ a 'demanding' form of co-operation that inevitably involves formal budgeting, possibly legal arrangements,¹² 'even common ownership of resources'.²³
4. *Support activities*¹⁷⁵ (e.g. integrated data systems²³), to produce informational continuity. Standardised electronic records have considerable potential to ease transitions between organisations²²¹ and to improve communications between them,¹⁵¹ including at clinical level (e.g. case conferencing⁶³), although the reality of health IT systems often falls short of this and IT systems are no substitute for oral communication.²²¹

The network co-ordinating bodies may be either separate from (e.g. NHS referral hubs) or incorporated into (e.g. CCGs) the local or regional bodies responsible for overall health-system governance. Such a body can also co-ordinate the providers' work^{61,219} at strategic and/or managerial and/or service delivery levels to ensure access for all the (eligible) population and efficient operations, and to 'maintain overall accountability for service, quality and cost outcomes'.²³ These activities require 'collaborative competence' in handling the problems that typically occur in collaboration.¹²² Such competences include communication with other agencies (necessary for establishing clear roles and responsibilities), understanding other agencies' goals,¹² arbitrating over any disagreements and harmonising working practices across the member organisations.¹⁸⁸ Sustaining care networks requires 'outcomes-based advocacy' (celebration of network achievements), 'vision-focus balance' (between goals and practical activities), systems orientation ('big-picture' understanding of the complex, systemic nature of community care) and community linkages.²²² Over time, trust develops between providers, and concomitantly territoriality and competition among them reduce,¹² which aids in the transfer of tacit and informal knowledge.

Disease management programmes are a special case of the managed network. Interventions to improve care co-ordination may be more effective when focused on particular risk factors in comorbid conditions or on functional difficulties in multimorbidity.²²³ Disease management schemes focus on patients with a single main diagnosis⁶⁴ and often include supported self-care³ or the use of nurses as care co-ordinators. Often they develop partly because of the inadequacy of GP-based care co-ordination.⁵

US evidence suggests that disease management programmes improve chronic disease outcomes, but not necessarily care co-ordination.²²⁴ A meta-analysis of disease management combined with case management (see below) found that improved disease control was associated with educating the providers, reminders and feedback, with education of patients and with incentives.²²⁵ A systematic review of disease management for depression found evidence of improvements in depressive symptoms and greater adherence to treatment, but more admissions to hospital and increased costs.²²⁶ An Australian disease management programme based on generic assessment by nurses, but retaining GPs as care co-ordinators providing mentoring for eight (somewhat overlapping) care groups, produced small improvements in Short-form 36-item health survey scores.⁶⁴ In England, a disease management programme for patients with coronary heart disease and heart failure, administered through nurse clinics, produced the small gain of 0.03 quality-adjusted life-year (QALY) per year at an incremental cost of £13,158 per QALY compared with a control group,²²⁷ although this ratio easily met the National Institute for Health and Care Excellence (NICE) criterion of cost-effectiveness.

Disease management programmes thus appear well adapted to providing flexible, informational and access continuities of care, at least for the focal disease, and perhaps also relational continuity, but are ill suited to providing holistic continuity.²²⁸

'Vertical' networks to manage hospital referral and discharge are often assumed to reduce unnecessary hospital admissions, making case management attractive to payers wanting to avoid the costs of unplanned hospital admissions.³¹ In the USA, managed care involves utilisation controls and management practices (e.g. clinical guidelines, disease management programmes, reports on referrals, tests and admissions) that make primary care preventative services available to patients, but also restrict which other treatments or providers patients may access. Some of these schemes were implemented through a predetermined, selectively contracted care network of providers and negotiated lower prices from doctors wishing to join the network.²²⁹ Some US attempts to introduce managed care through HMOs foundered on the problems of information sharing, transaction costs and fragmented provider interests.²⁰ Managed care schemes have also been tried in Germany, but with limited success in recruiting patients.⁶⁰ Such schemes did reduce preventable admissions of over-65-year-olds compared with non-managed care, especially for the more ill patients,¹²⁷ thus helping to control health-care costs.²³⁰

When patients leave hospital, primary care doctors can reduce the risk of unplanned readmission by contributing to a structured hospital discharge plan, reconciling hospital-prescribed with primary care-prescribed medications, and making an early assessment of the patient's follow-up needs and resources. The hospital's contribution is to initiate this plan, sending electronic discharge notifications and structured discharge summaries to the primary care doctor.²³¹ Preen *et al.*²³² described such plans being copied to the GP for review and then to the patient and other service providers. The GP made an appointment for the patient to attend within 7 days of discharge. Patients whose discharge was managed in this way rated discharge care arrangements as more 'achievable', were more satisfied with their input into discharge procedures and had a higher mental quality of life 7 days after discharge than patients who were discharged in the usual way. Medicare is introducing bundled payments to physicians to co-ordinate patients' care on discharge from hospital and to provide a practice appointment 7–14 days after discharge.²³³

Barriers to care co-ordination by network

Care co-ordination by network involves additional problems and tasks to those found within an integrated organisation:

1. To patients' transitions between professional silos and between primary and secondary care, a care network adds transitions across organisational boundaries. Potential conflicts of interest and in cultures between organisations are added to those between professions. Differences in provider ownership compound the scope for conflict (see *Appendix 2*). Conflicting expectations about the role of liaison or link workers, and about appropriate referral criteria, increased professionals' role ambiguity and impeded the work of mental health-care networks in England and Canada.¹⁵¹ Explanations of under-co-ordination in care networks adduce 'the costs, time and resistance to reduction in autonomy perceived by individual providers and services [...] differences in culture and ways of working'.³³ Systematic reviews that compare normal care with as many studies as they can find of a chosen model of 'comprehensive' or 'integrated' care, taken en bloc,⁹² often disregard these organisational differences; one reason, perhaps, why they often find the overall pattern of results 'inconsistent'.
2. Networks wishing to strengthen informational continuity have to surmount the original separation of IT systems in each member organisation.³³ Heavier inputs of administrative time are required for running discrepant information systems for bookings, record keeping, audit and monitoring, although good software can mitigate these difficulties.²¹⁷ In England, NHS and social care departments use different IT systems. Social care departments also use different IT systems among themselves, with no common coding system.²¹¹

Care networks' co-ordination structures are added to those that exist within each member organisation, as are transfers across probably less harmonised interfaces. Often 'invisible', the greatest of the resulting transaction costs are those that arise from the failure of care co-ordination to occur at all. Transaction cost theory predicts that where services have uncertain outcomes, frequent non-standard interactions and asset specificity, markets (and by implication networks of market partners) evolve into hierarchies, which in these circumstances are more economically efficient.²³⁴ These conditions are typical of care groups with

long-term chronic multimorbid health problems. If that is the case, care networks may tend to evolve into integrated organisations, for instance in the way that a predominant provider in a care pathway diversifies into upstream and downstream activities.¹⁸⁵ Gradually, care networks may develop from information exchanges to running joint projects, changing 'systemic rules' and altering the health system as a whole.²³⁵

Continuity, co-ordination, integration

On balance, the foregoing overview might seem to suggest that an integrated organisation containing a wide range of services (above all, primary medical care) is more likely to favour the development of care co-ordination, and therefore continuities of care, than co-ordination by care network. An integrated organisation inherently pools the funds for the different areas of its work,¹³⁵ in theory giving it an incentive to provide whichever services are most suited to the patient and most economical overall,²²⁰ irrespective of the existing division of labour¹³⁵ and without concern for the internal distribution of costs. The foregoing analysis implies various of further hypotheses comparing the effects of each main variant of integrated organisation and care network on continuities of care:

1. In organisations that horizontally integrate services by means of the 'consultation model', patients will experience:
 - i. high cross-sectional continuity of care
 - ii. high relational continuity of care from the *captant* professional, but lower relational continuity of care from the *non-captant* professionals
 - iii. high informational continuity of care, and
 - iv. high longitudinal continuity of care, but
 - v. a level of flexible and access continuity of care which depends on the range of services integrated within that provider.
2. In organisations that horizontally integrate services by means of an internal interdisciplinary team, patients will experience:
 - i. high cross-sectional continuity of care
 - ii. low relational continuity of care, unless the organisation is small
 - iii. high informational continuity of care, but more within than between professional 'silos', and
 - iv. high longitudinal continuity of care, but
 - v. a level of flexible and access continuity of care which depends on the range of services integrated within that provider.
3. In vertically integrated organisations, patients will experience:
 - i. high cross-sectional continuity of care
 - ii. low relational continuity of care
 - iii. high informational continuity of care
 - iv. high longitudinal continuity of care, and
 - v. high flexible and access continuity of care.
4. In care networks that rely on virtual ('functional') integration, patients will experience:
 - i. low cross-sectional continuity of care
 - ii. low relational continuity of care
 - iii. low informational continuity of care
 - iv. low longitudinal continuity of care, and
 - v. high flexible and access continuity of care.

5. In networked disease management programmes, patients will experience:
 - i. low cross-sectional continuity of care
 - ii. low relational continuity of care
 - iii. high informational continuity of care for the focal disease, but otherwise low informational continuity
 - iv. high longitudinal continuity of care for the focal disease, but otherwise low longitudinal continuity, and
 - v. high flexible and access continuity of care for the focal disease, but otherwise low flexible and access continuity.

6. In case management through a network of providers, patients will experience:
 - i. low cross-sectional continuity of care
 - ii. high relational continuity of care from the case manager, but lower relational continuity of care from other professionals
 - iii. low informational continuity of care
 - iv. high longitudinal continuity of care, and
 - v. high flexible and access continuity of care.

To represent integrated organisations and care networks as complete alternatives would be simplistic, though. Both are required, and they complement each other. Indeed, care networks have their advocates,²³⁶ who argue that these networks preserve provider autonomy while maintaining safeguards against the uncertainties and opportunism found in markets.²⁰ Care networks, it might be argued, are characterised by the use of information (feedback), organisational learning (iterative problem solving), distributed leadership (maximising stakeholder connection) and joint problem-solving, and are thus well adapted to handling 'wicked' problems.²³⁷

As we have seen, few studies describe the relationship between organisational structures and integration of care at the clinical level. At the wide margin where both are feasible, the question remains whether care co-ordination is likely to be easier, and hence more fully achieved, through care networks or integrated organisations. Perhaps well-functioning care networks would co-ordinate care better than ill-functioning integrated organisations. This brings us to our research questions (RQs).

Chapter 3 Aims and research questions

Aims

The aims of this study were to identify how the care co-ordination mechanisms in use in the main NHS services produced continuities and discontinuities of care; how NHS organisational structures constituted and constrained these co-ordination mechanisms; and how, therefore, these structures affected patients' experiences of the continuities and discontinuities of care. We also aimed to explore these issues in respect of certain types of organisational structure that barely exist in the NHS, but which (for the reasons outlined below) appear relevant to NHS-like systems and appear, *prima facie*, to have different impacts on continuities and discontinuities of care than do existing NHS structures. The scientific value added of this study – if successful – would lie not only in its empirical findings (some supplementing, others corroborating earlier studies) but in its explanatory character, tracing how organisational structure produces patient experiences of continuities or discontinuities of care. Besides these scientific aims, we had the practical aims of identifying steps that NHS managers and clinicians might take to improve the co-ordination and continuity of care, and of widening the choice sets that they might consider for that purpose.

Research questions

Our RQs were, therefore, as follows:

1. What differences does the integration of primary care into hierarchical governance structures make, compared with network governance, with regard to:
 - continuity of primary care (horizontal integration)
 - substitution of primary for secondary care (vertical integration)
 - the availability of management information about unit costs of care episodes and management costs
 - diversity of primary care services?
2. In the case of hierarchical governance, what difference does ownership make?
3. How much scope does either type of governance structure allow for managerial discretion and 'performance'? Within each, which managerial practices tend to promote continuity of primary care, substitution of primary for secondary care and diversity of primary care services?
4. Do the answers to RQs 1, 2 and 3 tend to support or refute the predictions (outlined above) about the differences between networked and hierarchical governance in regard to the continuity and integration of primary care?
5. What are the implications of the above for managerial practice in primary care?

Given the conceptual confusion surrounding many discussions of these topics, we must explicitly define some key terms. We define 'integration' as organisational integration; that is, a united structure of staff all working under common management (irrespective of whether the organisation has one owner or is jointly owned, e.g. by the NHS and local government). This is a narrower definition than in those policy, even research, discussions that describe almost any collaboration between separate organisations as 'integration'. Although our RQs focus on hierarchical governance, an organisation can instead be a

democracy, professional partnership or charitable foundation, or have yet another governance structure. Insofar as these alternatives exist in primary care, we consider them too in addressing our RQs. As 'substitution of primary for secondary care' we count two things:

1. partial substitution: shortening lengths of hospital stay at either end
2. complete substitution: replacing whole hospital stays entirely with non-hospital care.

We define primary care as all forms of care that patients can either access directly (hence including ambulance, out-of-hours, ED, pharmacy and other walk-in and online services) or that they can use while continuing to live in their normal home (hence including district nursing, help with the activities of daily living, most of the therapies, health-related social care, etc., and of course self-care). We do not equate primary care with general medical practice, although that is obviously often a pivotal component of it. We take managerial 'performance', 'action' and 'exercise of managerial discretion' as equivalent terms, and take 'management' to include the clinical management of the patient besides 'general' management. (Clinical practice itself is outside our remit.) Lastly, the term 'GP' is ambiguous between:

1. a doctor giving primary medical care
2. a doctor who is a partner in a professional partnership
3. a non-partner doctor employed by a professional partnership and
4. a doctor in single-handed practice ('free professional').

We restrict the term 'GP' to professional partners and otherwise say 'primary care doctor' (e.g. when speaking about doctors employed by private firms, in Swedish-model polyclinics, etc.). This is a narrower definition of 'GP' than usual but for organisational analysis, and our RQs in particular, these distinctions are important enough to warrant a verbal label.

We have provided a glossary to clarify how we have defined this and other commonly used terms in this field.

Chapter 4 Methods

Design

Our methodological strategy reflected the nested character of the structures through which care is co-ordinated. We started from an analysis of patients' experiences of continuities of care, and then traced the organisational-level co-ordination mechanisms that produced those experiences. From the provider level we worked 'outwards' again to the care network mechanisms for co-ordinating care across different providers. Using Øvretveit, Hansson and Brommels' ideas³³ but reversing the direction of analysis, we worked back from 'consequences for clients' to 'consequences for personnel' to 'coordination structures'; an 'inside-out analytic strategy'²³⁸ moving from a particular to an ever-broader view of the local health economy at each study site.

This strategy required three main pieces of knowledge:

1. Patients' experiences of care co-ordination, from their own accounts, their health-care records and administrative data. (Assessment of clinical outcomes was beyond the scope of this study.)
2. What care co-ordination mechanisms were available to that care group in that setting, and what barriers to co-ordination existed, knowledge obtainable from the practitioners and managers responsible for the care group.
3. What effects each of the observed co-ordination mechanisms (or barriers) has on the continuities of care.

This study empirically examines points 1 and 2 in NHS and NHS-like settings. *Chapter 2* gave an overview of the extensive though still incomplete evidence base regarding point 3.

To discover what care co-ordination mechanisms exist in a given setting, how each mechanism produces continuities or discontinuities of care and how patients experience them requires multiple qualitative methods; our study design follows Alexander and Bae's recommendation⁷⁹ for researching the similar context of the US patient-centred medical home. Our multiple-methods design combined five main methods:

1. *Assembly of an analytic framework* by non-systematic review of existing research. This contributed directly to answering RQ 4 and indirectly to answering the other RQs.
2. *A framework analysis of patients' experiences of the continuities of care* in the same sites as the organisational case studies (see below), using patient interview data and, as validation, quasi-quantified (patient records) data, and comparing the findings with the co-ordination mechanisms described in the organisational case studies. This contributed to answering RQs 1 and 4.
3. *A systematic comparison of organisational case studies*, applying the above analytic framework to a maximum-variety sample of care co-ordination mechanisms (organisational structures, care network structures, models of care, managerial practices). This contributed to answering RQs 1, 2, 3 and 5.
4. *A cross-country comparison* of care co-ordination mechanisms found in our NHS study sites with Swedish polyclinics whose care co-ordination structures are absent from the NHS. This contributed to answering RQs 1, 2 and 4.
5. *Synthesising* the above empirical findings so as to answer all four empirical RQs and correct our initial hypothesis about the relative merits of integrated organisations and care networks as means of care co-ordination (RQ 4).

Stage 1 above corresponds to the theory-building and modelling stages for evaluating complex interventions, our empirical work to the exploratory phase.^{239,240} *Table 2* shows the methods, data and analyses for each RQ.

TABLE 2 Research questions, methods, data and analyses

RQ	Method	Data sources	Analysis
1. Differences between integrated and networked structures regarding continuity of care, substitution, vertical integration, cost information, provider diversity	Systematic comparisons of organisations and care networks regarding: 1. Patterns of patient experience 2. Care co-ordination mechanisms	1. Organisational case studies 2. Patient interviews 3. Patient records 4. Peer-reviewed secondary studies	Compare patterns of patient experience of dis/continuities of care with the care co-ordination mechanisms reported in the organisational case studies
2. Implications of ownership	Systematic comparison of care co-ordination mechanisms in corporate, professional partnership and publicly owned primary care medical services	1. Organisational case studies 2. Peer-reviewed secondary studies	
3. Scope for managerial discretion and performance	Collate evidence across study sites of the scope and care co-ordination uses of managerial discretion	1. Organisational case studies 2. Peer-reviewed secondary studies	Abstract from organisational case studies any evidence of uses of managerial discretion that affect care co-ordination
4. Predictive implications	Compare answers to RQs 1, 2 and 3 with initial analytic framework	Aggregation of the above	Falsificationist: seek points where the above analyses falsify, qualify or corroborate the analytic framework
5. Implications for managerial practice	Filter answers to RQ 3 for instances of uses of managerial discretion that appear to increase continuities of care	1. Organisational case studies 2. Peer-reviewed secondary studies	Abstracted from answers to preceding RQs

We also compared our own findings with relevant empirical findings emerging from research studies in the Health Reform Evaluation Programme, Health Services and Delivery Research (HSDR), NICE and Department of Health Health Policy Programmes.

The underlying methodology was realist; not realist evaluation, as our RQs did not require us to test the programme theories underlying current NHS policies for care integration,²⁴¹ but realist in the sense of attempting to expose, characterise and compare alternative organisational and network mechanisms for care co-ordination.²⁴² It was also falsificationist,^{243,244} in that we first formulated a set of theories and hypotheses about care co-ordination and then compared these with our new evidence, revising and refining those explanations as that evidence dictated. In that way we also confronted the issue of reflexivity; that is, of being aware of the preconceptions (explanatory assumptions) that we brought to the data, and looking for errors in those.

We involved patient representatives, recruited and supported by the Patient and Public Involvement Team from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula (PenCLAHRC). We worked with them before the research started on both a group and an individual basis, looking at the form and content of the patient information and interview schedules, and we will involve them again in the post-project dissemination activities. We will also involve study site managers in disseminating our findings, focusing at the outset on the NHS research and development offices for our case study sites and our original key informants.

Initial explanatory and analytic framework

We assembled our initial analytic framework (see *Chapter 2*) from a review of existing research, whose findings we categorised, linked and thematised ‘by a process of gradual abstraction’.²⁴⁵ The review was non-systematic because it addressed three tasks for which systematic reviews are not designed; that is, to:

1. assemble theories about what organisational arrangements produce care co-ordination
2. identify care co-ordination mechanisms that appeared relevant to our focal care group but are not used in the NHS
3. operationalise our RQs, and hence focus the empirical research.

The review was a realist synthesis in that it attempted to synthesise what is so far known about the mechanisms for achieving care co-ordination, their contexts and outcomes. However, it was not free standing. Its findings were intended to inform, and to be tested through, the other research methods noted above. So, after *Chapter 2* they are not presented separately from those produced by the other methods we used. With that qualification, our methods conformed to the Realist And MEta-narrative Evidence Syntheses: Evolving Standards (RAMESES) recommendations.⁷⁷

We initially scoped the literature by searching for the most recent systematic reviews in the relevant fields (e.g. about care plans, polyclinics, etc.). Where recent (≤ 10 years old) reviews existed, we focused our search for primary studies on the period following the reviews. Otherwise, we placed no time limits on our search. Except for very specific keywords (e.g. ‘care plan’ or ‘primary care team’), hand-searching journal contents lists and snowballing back from one study to another often revealed more studies than did automated searches (e.g. of PubMed or Google Scholar) of this conceptually and terminologically ill-defined literature. We hand-searched journals dedicated to primary care co-ordination (e.g. *International Journal of Integrated Care*), those which focus heavily on clinical practice (but not necessarily on care co-ordination) in primary care (e.g. *British Medical Journal*, *British Journal of General Practice*), and those which focus on health policy and its implementation in fields relevant to care co-ordination (e.g. *Social Policy and Administration*). We also hand-searched policy and think-tank websites (e.g. Department of Health, The King’s Fund) for peer-reviewed studies.

Given our ‘inside-out’ analytic strategy, we started assembling the theoretical framework in *Chapter 2* by conceptualising (as others have²⁴⁶) a patient’s experience of complex care as a ‘journey’ along a care pathway (a de facto care pathway, even when it is not formally documented): that is, as a process of production. This starting point gave us three ways of using existing research findings to formulate and define the hypotheses listed at the end of *Chapter 2*.

1. For some topics (e.g. conditions for effective interdisciplinary teamwork), sufficient studies – mostly qualitative – existed for some overall empirical patterns to be recognisable.
2. Beyond the health sector, certain more general organisational theories (reviewed in an earlier NIHR study²⁴⁷) report which characteristics of a production process constrain, and which are constrained by, the organisational structures used to manage it. Among these characteristics are how uniform and standardised the process is; how far it can be mechanised; whether it is continuous or episodic; what skill mix it demands; and whether its component subprocesses occur sequentially or in parallel. Different combinations of these characteristics imply that a specific kind of organisational structure will ‘fit’ best for managing each kind of productive process.^{163,248} Research on interorganisational networks reports what patterns of interorganisational linkage appear conducive to effective and efficient interorganisational collaboration in health care.^{32,188,249} Some of the studies cited in *Chapter 2* appeared to describe instances of these wider organisational or network patterns. One could then infer corresponding hypotheses about what effects these specific characteristics of primary care processes, organisational structures and interorganisational networks would have on primary care co-ordination and continuities.
3. Where there were few empirical studies and none of the wider theories seemed applicable, hypotheses had to be formed by analytic (qualitative) generalisation,²⁵⁰ the weakest of these three methods.

Given our RQs, we above all formulated hypotheses about what effects their context (integrated organisation vs. network) was likely to have on the operation of mechanisms intended to produce care co-ordination and continuity. By the time the data analysis and synthesis were completed, we had revised our initial framework in several ways, reported in *Chapter 11, Revisions to the initial analytic framework* (an 'open-ended' analysis²⁵¹).

Case studies of organisational and care network co-ordination mechanisms

Applying the above analytic framework, we systematically compared case studies of a maximum-variety sample of care co-ordination mechanisms (organisational structures, care network structures, models of care, managerial practices). This contributed to answering RQs 1, 2, 3 and 5.

Sampling

Although we intended to trace back from patients' experiences of the continuities of care to the co-ordination structures that produced them, our aim was to contrast different types of co-ordination structure. We therefore selected a theoretically based, purposive maximum-variety qualitative sample of study sites, chosen as follows to instantiate the main types of co-ordination structures identified in our RQs:

1. *Hierarchy, public ownership*. Ideally, this would be a single, integrated organisation providing primary medical care, CHS, mental health services and social care. However, no such organisation existed in the NHS at the time of our fieldwork.
 - i. The nearest NHS equivalents were trusts or foundation trusts that combined CHS provision with hospital services and/or mental health services and/or social care.
 - ii. In Sweden, however, such organisations did exist: the *vårdcentral* described in *Chapter 10*.
2. Two types of *care network* ('federated') structure pursuing the objectives originally proposed for English 'polyclinics' by combining:
 - i. General practices and CHS.
 - ii. CHS and social care providers (sometimes with GP participation).
3. *Hierarchical, privately owned* commercial or joint-venture primary care providers. We selected a corporate private practice whose owning company also provided other primary and CHS in the same locality.
 - i. A hybrid partnership, hierarchical and care network structure: concretely, the standard tripartite NHS model, as a reference point.
 - ii. A *privately owned medical practice networked with public CHS*. In the event, the study site mentioned at (3) also satisfied this criterion, since that general practice was networked with NHS-owned CHS and other providers. For further comparison we also examined (in less detail) a Swedish equivalent (see *Chapter 10*).

When our fieldwork began, no routinely published national data reported general practice ownership or the care co-ordination structures in each PCT (as local health economies then were). We therefore identified possible sites using the professional press (especially *Pulse*, *GP Daily News*, *Medeconomics* and the *Health Services Journal*), NHS Networks websites and mailing lists, Department of Health and think-tank websites, and national media (especially the BBC and *The Guardian* websites), supplemented with the researchers' own knowledge and networks. In consequence, we refined the sampling strategy stated in the study protocol to distinguish two models of federated (networked) primary care co-ordination: networks of professional partnership general practices (e.g. CCGs, general practice

'federations')⁴³ and networks of hierarchically organised public providers (confusingly, also called 'federations' in some places). During this period of greatly increased workloads for general practices, commissioners (and, therefore, NHS research governance administration) were also being restructured and restaffed. In all we approached 10 sites, and at the expense of much time and effort gained access to five, which together represented the main co-ordination structures that we needed to study.

These methods yielded the following sample of study sites in England. Three sites were whole counties, one was part of a county, and the fifth was part of a larger conurbation. We have pseudonymised the sites. Fuller details are in *Appendix 3*, but, briefly:

1. **Eastmere** instantiated the standard tripartite NHS co-ordination structure of separate primary medical care (professional partnership general practices), NHS trusts (CHS; acute hospital; mental health) and social services. The CCG divided its territory into 10 GP localities. The county council divided the same territory into six localities. Towards the end of the study period the county council was awarded integration pioneer status for its plans to join up health and social care services, and one study general practice was given a RCGP quality award. This study site was, therefore, a well-developed example of the standard model.
2. **Whinshire** was selected for its large, elaborate managed network for co-ordinating care across provider organisations. CHS and mental health services were integrated into a single NHS trust which, until 2012, also provided social services on behalf of the county council (under a §75 agreement). Thereafter, the site reverted to colocated, separately managed services, which had separate data holding but retained a shared referral model. It hosted a personal health budget pilot scheme. Its care network originated from a collaboration between the local practice-based commissioning group and the PCT, and developed into a community interest company. By the time of our fieldwork this network involved nearly all of the general practices in the county, all of the other health-care providers, and social services.
3. **Sedgeton** was selected for its virtual 'polyclinic' housing networked colocated services – that is, organisationally separate community health, acute hospital outpatient and mental health services, all in one building, with mental health inpatient facilities next door. Links were developing with social care. The general practices referring to all of these services were part of a 'federation' including these and other providers. Our case study practices were two of those that referred most patients to the colocated services.
4. **Tarrow** was a vertically and horizontally integrated health and social care provider (hierarchical governance) with an acute hospital, CHS and adult social care (under a §75 agreement), all managed by one chief executive. Mental health services were provided by a separate trust. When the §75 agreement ended, adult social care services reverted to separate county council management. Two virtual ward schemes were being piloted and, later, integrated health and social care personal budgets.
5. **Fivecastles** contained a corporate general practice belonging to a company that provided other primary and CHS in the county (hierarchical governance). The county also had a combined hospital and CHS trust. The general practice, integrated community and acute trust and mental health trust were, thus, three separate hierarchies, externally networked to each other.

Every site had a NHS treatment centre, a NHS ambulance trust and commercial and third-sector service providers, vertically integrated mental health services and, of course, other professional partnership general practices.

In each site integrated organisations and care network structures coexisted, and the organisations were components of care networks. Following the care process logic of our analytic framework (see *Chapter 2*), *Table 3* summarises which structures coexisted. In each row, the bodies listed in the 'Care network' column co-ordinated the providers listed on either side of them. Where a combined organisation provided normally separate services during part or all of the study period, *Table 3* brackets them together.

TABLE 3 English study sites: organisations and care networks. Services bracketed together were provided by a single organisation

Site	First responder studied	Care network management bodies	Second responders
Eastmere	Partnership general practice	1. Emergency intervention service (referral hub)	1. CHS 2. Hospitals 3. Mental health 4. Social care
Whinshire	Partnership general practice	1. Proactive care 2. Elderly crisis hub: entry point for intermediate care team	1. {CHS + mental health combined} 2. Hospitals 3. Social care
Sedgeton	Partnership general practice	1. IPCTs 2. Rapid discharge team 3. Federation of general practices and other providers 4. Well-being service	1. CHS 2. Hospitals 3. Mental health 4. Social care
Tarrow	Partnership general practice	1. Virtual ward scheme 2. Older persons' community mental health team	1. {CHS + hospitals + social care combined} 2. Mental health
Fivecastles	Corporate hierarchy	1. Multiagency group 2. 'Gold-standard' palliative care teams 3. Preventative health and social care providers network	1. {CHS + hospitals combined} 2. Mental health 3. Social care

IPCT, integrated primary care team.

In each site we assembled a sample of key informants based on our patient interviews and discussions with a practice manager or GP, who in turn suggested further informants relevant to the study. This snowballing method yielded the sample of 80 informants summarised in *Table 4*.

Data collection

Data were collected from informant interviews (using the schedule given in *Appendix 4*) and managerial documents. Unless the interviewee requested otherwise, all interviews were digitally recorded and professionally transcribed, and interviewees were offered the chance to correct their transcript. Our findings chapters (see *Chapters 5–9*) identify these informants by the relevant case study prefix (E–W), followed by the letter P (for 'practitioner') and a numerical identifier. Our collection of managerial documents was guided by our interviewees, as they were best placed to say which documents were locally seminal. We also collected professional press reportage.

TABLE 4 Organisational informants

Organisational role(s)	Eastmere	Whinshire	Sedgeton	Tarrow	Fivecastles
General practice (GPs, other staff)	2	3	2	2	4
Care network co-ordinators	2	4	3	3	3
NHS trust managers and clinicians	13	7	7	4	6
Social care	1	1	1	1	1
Other	3	2	2	1	3
Total	20	17	15	11	17

Initial analysis

We collated data about each organisation's and each network's care co-ordination mechanisms against the relevant headings in the analytic framework (*Table 5*), adjusting these categories when necessary.

Collating data against a prior framework revealed where any mechanisms described in the analytic framework were absent. It also provided a structured means of data triangulation so that we could supplement our data with ad-hoc e-mail and telephone enquiries when the data had gaps or ambiguities, or if we had reason to believe that circumstances had changed at a particular site. From any remaining data we inducted patterns, supplementing the analytic framework as necessary. Following the care process logic outlined above, we differentiated the care co-ordination structures and mechanisms found in the following:

1. first-responder organisations at each site
2. care networks and their managing bodies
3. main second-responder provider organisations, insofar as they contributed to the care of our focal care group.

Because of how the NHS is structured, this approach approximately corresponded to and analytically separated three contrasting governance structures for care co-ordination: professional partnerships (most general practices), networks (referral hubs, virtual wards) and hierarchies (NHS trusts, social services).

TABLE 5 Data collation framework: organisational case studies

Main theme	Subtheme
Care co-ordinator(s)	
Care planning	Care plan Seeking review and handling risk
Information transfer	Records: access/openness Governance
Service profile	Shortages Specialised services Professional silos, trust, cultures
Onward referral	Maintaining continuity of access
Co-ordination mechanisms	Regular meetings
Managerial and clinical action and discretion	Ethos and leadership Care process redesign Cost
Substitution of primary for secondary care (vertical co-ordination)	Admission avoidance, early intervention Discharge planning
Context	Policy imperatives Diversity of providers/services Ownership: higher level controls on managers, clinicians

Patients' experiences of continuities and discontinuities of care

Sampling

As we wanted to trace the connections (and disconnections) between patients' experiences of the continuities of care and local organisational and network structures, we sampled patients in the same study sites as the organisational case studies. We also needed to sample patients who had recently experienced complex care and hence who satisfied the following inclusion criteria:

1. being 65 years of age or older
2. having complex health-care needs, defined as having at least two of the following conditions: arthritis; heart failure; COPD; stroke; mental health problem (depression, dementia, psychosis, schizophrenia or bipolar disorder); and sensory deprivation (blind or deaf)
3. receiving care for at least 1 year before the study from at least two provider organisations
4. living in own home or with family.

Exclusion criteria were:

1. having a moderate or severe learning disability
2. receiving terminal care
3. being in the criminal justice system
4. being unable to give informed consent
5. being too frail to give an interview
6. living in residential care.

Our nine chosen GP practices each drew a sample of patients conforming to these criteria and sent out invitations, study information and reminders on our behalf. Patients who were interested in participating were then able to contact the research team using the reply slip and prepaid envelope supplied or, on occasions, by e-mail, telephone or their GP surgery. Because we intended to characterise patients' experiences of the continuities and discontinuities of care qualitatively, we interviewed small numbers of patients in depth until we approached data saturation ($n = 66$; *Table 6*). Interviews typically lasted about 45 minutes and, given the patients' age and interest in the topic, often became somewhat discursive.

TABLE 6 English study sites: patient interviewees

Site	Number	Age range (years) ^a	Mean number of chronic conditions per patient	Most common conditions
Eastmere	13	62–91	3.3	Arthritis, restricted mobility, incontinence, heart disease
Whinshire	12	63–91	4	Heart disease, diabetes, mental health problems, cancers
Sedgeton	14	66–89	4	Arthritis, restricted mobility, pain, anxiety/depression
Tarrow	14	66–96	4.4	Heart disease, restricted mobility, diabetes, gastrointestinal
Fivecastles	12	72–85	3.5	Heart disease, arthritis, diabetes

^a Their medical records showed that two of the patients selected for us were not yet 65 years old at the start of the study (but were at its end). However, both were retired and their combination of long-standing comorbidities was considered to justify their retention in the study.

The wide inclusion criteria meant that patient characteristics varied across the study sites (see *Chapter 5*). The decision to take the patient as the starting point for the research meant, however, that they had not necessarily used the care networks that practitioners and managers subsequently described. For example, although the Sedgeton patients had all used services at the 'polyclinic', none of the Tarrow patients had used the virtual wards, as many lived beyond the relevant catchment area. Similarly, whereas the Eastmere interviewees were the most limited group in terms of activities of daily living and received the most social care support, Fivecastles was, in contrast, an affluent area with patients who were:

[. . .] very good at going and helping themselves [. . .] well supported by helpful, intelligent and well-resourced families.

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None of the Fivecastles patients had current social services or care agency support. Several had used private health care or local private hospitals. Patients in Eastmere, Tarrow and Fivecastles lived in 'predominantly' or 'significantly' rural areas, but the Whinshire patients lived largely, and Sedgeton patients lived entirely, in urban areas.

Data collection

Patient interviews were conducted using a semistructured interview schedule (see *Appendix 5*). With patients' consent, their interviews were digitally recorded and transcribed professionally. When patients wished, their carers (for one, his 93-year-old sister; for two others, their spouses; and for another, his son) were present and contributed. We extracted data from the interview transcripts into a standard pro forma (*Table 7*), a deductive coding frame.

Free-text answers were thematically coded by the researcher who had conducted the field interviews [initially using NVivo (QSR International, Warrington, UK)] and then passed for validation to the principal investigator. One case study site was initially also coded by a third member of the research team to test for consistency of approach. Patient-level data were then collated into a site-wide form of *Table 7*, with additional categories suggested by the inductive analysis, so that patterns across patient experiences, and differences, could be seen. We also made an emergent (inductive) coding of the responses that the initial deductive coding framework could not accommodate, which included many of the more unstructured, 'free' responses. These additional codes (e.g. patient willingness to co-ordinate own care) and the coding of any ambiguous responses were agreed between the principal investigator and the researcher(s) most acquainted with the study site. We thus conducted both a framework and an inductive ('ground-up') analysis of the interview data.

Information on health care and referral pathways across the past year was perhaps the most difficult for patients to recall:

Interviewer: *Who called the ambulance for you?*

Patient: *I don't know. When I woke up the ambulance was here.*

Interviewer: *Did they take you to [hospital name]?*

Patient: *[Hospital name].*

Interviewer: *So how long were you in [hospital name] for?*

Patient: *I can't say – I can't remember.*

E13

TABLE 7 Data extraction template: patient interviews

Main theme	Subtheme: evidence for presence or absence of
Care manager	Patient knowledge of her/his care manager Relational continuity Longitudinal continuity
Care planning	De facto care plan Appropriate onward referral Team working
Care review	Monitoring Flexibility as patient's needs change
Patient's contribution to care co-ordination	Willingness to be own care co-ordinator Patient sufficiently supported/informed/involved Difficulties of self management Patient asking for care
Uninterrupted care	Continuity of access Waiting times Patient given adequate follow-up, instructions Early discharge
Information transfer	Informational continuity Transfer of information/communications between providers Providers' use of information Providers' accumulated knowledge (including patient's preferences, lifestyle, social context)
Substitution of primary for secondary care	Care closer to home/telemedicine Secondary treatment in community Secondary care in community (e.g. acute care/hospital at home, virtual wards) Admission avoidance/early intervention, discharge planning
Cost	Cost savings Wasted time, resources Poor-quality/unsafe care Patient outcomes Family burden/satisfaction Provider compliance with referral request
Diversity/structure/range of services	Where referred to Resources available Resources lacking (e.g. treatments/services not provided)

As validation and to obtain further data we therefore undertook a content analysis of the medical record for each patient for the preceding year, extracting data about three basic activities from the patient's general practice record into a standard pro forma (*Table 8*):

1. encounters between general practice and patient (e.g. consultations, treatment and review in the surgery, home visits, telephone calls)
2. actions in which the practice engaged with external providers on the patient's behalf (e.g. referrals, requests for advice, case meetings), usually without the patient being present
3. patient encounters with other providers (transfers), typically documented as reports, reviews, treatment, information, advice and discharge notices.

In extracting data we focused on pro tem transfers of responsibility for care between the patient, clinicians and organisations. We did not extract data about requests for repeat prescriptions, did-not-attend notices or practice requests to make appointments for, for instance, chronic condition reviews; we extracted data only about the resulting encounter. These data describe the activity captured by general practice medical records (and hence information readily available to GPs) but will tend to under-report community and social care, and will omit undocumented activities. In one practice, for example, CHS staff had read/write access to the GPs' records, and so CHS activity was more fully recorded there. Practices had different ways of recording information depending, for instance, on which electronic system they used, practice protocols and individual idiosyncrasies. (One GP might, for example, write very full notes including a description of a patient's holiday; another might write sparse notes relying heavily on abbreviations.) As with practitioner interviews, extracts from patient interviews are indicated by a case study prefix (E–W) and numerical identifier. Medical records are indicated in the same way, but with the additional letters MR ('medical record').

Initial qualitative analysis

Our analytic framework (see *Chapter 2*) listed observable features that would be evidence of continuity and co-ordination of care: the presence of a care co-ordinator and of a care plan; an ongoing relationship between care co-ordinator and patient; reviews; access to services; and information transfer. Combining the interview and medical records data for each patient, we checked for the qualitative presence or absence of each of these features in the patient's experiences. Applying the same headings and collating within each study site, we wrote for each study site a case study of care co-ordination there, as collectively reported by its patients. We noted any differences between patients' accounts, any aspects of care co-ordination not anticipated in our original framework, and the broad (qualitative) patterns of care co-ordination reported in the patients' medical records. By comparing these case studies, we could then qualitatively compare study sites.

Initial statistical analysis

Quantifiable data from patient interviews and the matching medical records were tabulated and coded onto a spreadsheet, including coding for additional (e.g. organisational) variables constructed that might explain any variations between study sites or sampled practices. Where data sets were large enough, we ran simple tests of correlation between activities and sites [using IBM SPSS Statistics version 21 (Armonk, NY, USA)], declaring p -value ≤ 0.05 as the significance level. [The findings chapters (see *Chapters 5–9*) report which data sets were large enough to be so analysed. In those chapters we use the terms 'significant difference' or 'no significant difference' where statistical tests were made. Without that qualification, terms such as 'difference' refer to qualitative differences.] Simple measures of central tendency and cross-tabulations ('crosstabs') were used. Depending on data characteristics, the tests applied were Pearson's chi-squared test, Fisher's exact test and analysis of variance. This analysis contributed to answering RQs 1 and 4.

TABLE 8 Data extraction from general practice medical records

Date	Condition	Originator					Recipient					
		Transaction type	Organisation	Location	Department	Role	Identifier	Transfer type	Outcome	Organisation	Role	CC'd

Cross-country comparison

Design

Given our RQ, the ideal comparator against which to compare care co-ordination by care networks would have been a single, integrated organisation providing primary medical care, CHS, mental health services and social care. The NHS had no such providers at the time of our fieldwork, but they did exist in Sweden. A comparison of care co-ordination mechanisms available in these two settings would contribute to answering our RQs 1, 2 and 4. For comparability, we used the same analytic methods as for the English case studies and reused secondary data from surveys of Swedish polyclinic directors about their management of four chronic diseases (coronary heart failure, depression, diabetes and asthma). We did not analyse patient records but did interview a small number of patients (not reported here).

Sampling

Using the researchers' own knowledge and networks to identify study sites, we selected the following PHCCs (polyclinics) whose organisational structures had no NHS equivalent:

1. three publicly owned, hierarchically structured polyclinics (*vårdcentral*) in Stockholm (Lisebergs, Kista, Djursholms läkarmottagning)
2. TioHundra AB, a vertically and horizontally integrated, publicly owned provider of hospital, primary care and social care (Norrtälje)
3. a not-for-profit trust providing primary medical care and other primary care services (Stockholms Sjukhem)
4. a corporation (private for-profit hierarchy) providing primary medical services (Solna Capio).

All were financed by Stockholms läns landsting (SLL: Stockholm county council). SLL directly line managed the three PHCCs under heading (1) above and commissioned the others through contracts. In size and function the PHCCs were similar to the larger NHS general practices.

Data collection

Data were collected (2011–13) at county and municipal (i.e. commissioner) and at provider level by mixed methods from the following sources:

1. Interviews and discussions with key informants. These included three representatives of SLL (polyclinic line managers and commissioners), the polyclinic head and two nurses at each provider, and at Norrtälje a half-day meeting with the polyclinic head for mental health services and three clinicians to discuss how care was co-ordinated across services. We interviewed six patients at the directly managed polyclinics, three at Norrtälje, four at Capio and two at Stockholms Sjukhem.
2. Grey material including official regulations and guidance.
3. Ad-hoc enquiries from individual experts.
4. Published research found by hand-searching journals.

Interviews were recorded and transcribed. Material from the Swedish study sites was obtained partly in Swedish and partly in English. The former material was translated or summarised for us by native Swedish speakers.

The surveys (2005 and 2011) replicated a US survey to discover the use of recommended care co-ordination practices and of IT for co-ordination in primary care.^{252–254} The response rate was 37%, with a bias towards the larger centres. Whether or not there was a higher proportion of public than private PHCCs replying is unknown, as there are no reliable national data about PHCC ownership.

Initial analysis

To enable comparison we made the same initial analysis of the Swedish as of the English organisational case studies. *Chapter 10* presents these findings.

Data synthesis

In all, we assembled the data summarised in *Table 9*.

We synthesised the initial analyses in four stages. The first three were systematic, in the sense of using the same analytic framework to structure and compare different sets of data. We continued to adjust the analytic framework in the light of unforeseen findings.

Nested framework analyses

Given our 'inside-out' study design, the framework analyses were nested in the following order:

1. We started from the findings (see *Chapter 5*) about patients' experiences of the observable features of continuity and co-ordination of care (see *Chapter 2, Processes and structures for care co-ordination*).
2. Next, we compared the pattern of patient experience at each site with the initial analysis of care co-ordination mechanisms in the first-responder organisations at that site. *Chapter 6* presents these findings. Where they matched, the organisational case study provided a prima facie explanation of patients' experiences. For example, patients often reported difficulties accessing 'their' preferred GP, whereas the general practices reported overloaded appointment systems and high GP workloads. Where patients reported discontinuities of care for which our case studies contained no apparent organisational explanation, we sought explanations in non-organisational causes²⁵⁵ such as patients' own resources and decisions. However, our health worker informants more often reported care co-ordination mechanisms, or the absence of such, not mentioned in the patient experience data (e.g. case reviews which the patient was unaware of). We consider in *Chapter 11* what that signifies.
3. We repeated step 2 for the case studies of the 'second-responder' provider organisations at each site. Again, we interpreted organisational case study findings that matched patients' experiences as being prima facie explanations of those experiences. *Chapter 7* presents the findings.
4. Next, we read off from our informants' accounts how care networks (and other factors) had influenced the providers' organisation and management. At this stage of the analysis the most informative data were usually our informants' narratives (a local NHS history) of how care networks had developed in each study site, the rationale for those developments and the practical constraints on them. *Chapter 8* presents these findings.
5. Finally, we traced the ways in which the governance of local health economies had shaped the working of the care networks. Here, too, informants' narratives of recent NHS history in the study site were often the most informative data. These findings are in *Chapter 9*.

At each stage draft analyses were circulated among the researchers acquainted with a particular study site, to check for accuracy, completeness and face validity. We systematically compared findings across study sites to reveal similarities and differences.

TABLE 9 Data assembly

Source	Interviews	Other material
Patients	66	64 medical records
English organisational case studies	80	160 documents and press reports
Sweden	40	Two surveys of polyclinic heads
Secondary data	N/A	760 published papers and research reports
N/A, not applicable.		

Systematic comparison of organisational case studies

We systematically compared the initial analyses of organisational and care network structures in order to find common patterns in care co-ordination mechanisms across sites, and differences between sites that might reflect differences in organisational and network structures, including any differences between care networks and organisationally integrated providers. We therefore compared:

1. sites where acute and community services were integrated into one organisation (Fivecastles and Tarrow) with sites where they were separate organisations (Eastmere, Sedgeton and Whinshire)
2. sites where community and mental health services were integrated into one organisation (Whinshire) with sites where they were separate organisations (Fivecastles, Eastmere, Sedgeton and Tarrow)
3. sites where community services and social care had been integrated into one organisation (Tarrow) with sites where they were separate organisations (Fivecastles, Eastmere, Sedgeton and Whinshire).

In this way we addressed RQs 1 and 3. By comparing these findings with our original analytic framework and hypotheses, we also began to address RQ 4. We furthermore systematically compared the corporate general practice (Fivecastles) against the professional partnership general practices in the other four sites, thereby addressing RQ 2.

Cross-country comparison

We extended the systematic comparison of English organisational case studies by adding in our initial analysis of the Swedish polyclinics. The methods and process of analysis were essentially as described above.

Inducting patterns of managerial discretion

Given our RQs, we filtered our organisational data for any that suggested ways in which managerial decisions had produced or frustrated continuities of care. For this purpose, 'bad' managerial decisions (reducing continuities of care) are as informative as good. We collated these findings across sites, thereby answering RQs 3 and 5.

Ethics and research governance

Ethical approval was obtained for the study from the NHS Research Ethics Committee system (reference 10/H0206/71), subject to informant anonymity and obtaining research governance approval from each research site, which we did for all the NHS sites. University of Plymouth ethical approval was obtained for non-NHS sites. All English sites, organisations, informants and patients are, therefore, given pseudonyms in this report. As noted above, obtaining permission for study site access was laborious and took many months. The growing importance of evidence-based policy-making contrasted with these obstacles to accessing the necessary evidence. No such difficulty arose in Sweden.

Chapter 5 Patients' experience of care co-ordination

Although the characteristics of the patients we interviewed varied considerably, they did not differ systematically between study sites. Just over half (55%) were female. A small majority (58%) lived alone and most (78%) lived in private housing. On average, patients reported four chronic health problems, most commonly heart disease, arthritis, diabetes and gastroenterological conditions (see *Table 6*). Patients tended not to mention problems such as impaired mobility or falls but these were apparent from, for example, their activities of daily living and health appointments. For many, such problems were increasing. Sixty-two per cent had experienced a major change in their health or personal circumstances in the last year, most commonly a new health problem or the intensification of an existing one. Consequently, most (77%) found difficulties with at least some activities of daily living, most commonly walking outside their home (65%) and being unable to drive because of poor health (42%). A further 11% had never learnt to drive. Difficulties walking typically ranged from breathlessness and discomfort through to an inability to walk more than a few yards alone. One respondent was unable to leave her bed. Such constraints on mobility pose a barrier to accessing health services without support. We asked patients to rank their current health status. The mode was the mid-point defined as 'okay' or '5/10'. Eighty-one per cent placed themselves at this level or lower. Despite these challenges, social services support was sparse. Just 14% currently had a care package. Another 18% had received equipment and home adaptations.

We first report our patient informants' experiences of care co-ordination, noting similarities and then differences across study sites. The terms 'significant difference' or 'no significant difference' indicate the result of a statistical test, and we report the relevant percentages in the data. Otherwise (i.e. without that verbal qualification and obviously without any corresponding percentages being shown), 'difference' refers to qualitative differences in the everyday non-statistical sense.

Common patterns across sites

Patients saw their general practice, or even a particular GP, as the obvious first port of call for help if they had a new or exacerbated health problem, with other first-responder services (out-of-hours service, ambulance, ED) as unavoidable proxies when their GP was unavailable.

Well when [GP name] first came I'd just had my first hip done and I had a bit of a [...] fall and I had the most terrible pain, it really was excruciating. I couldn't even lie down in bed it was so bad. So I went in and I saw two different doctors who happened to be on duty, I just went in and they gave me painkillers. And then I went in and I saw [GP name] and he said, 'Right well we'll have a bone scan and an X-ray,' and off I went and that was the difference. [...] Yes, I like to see him, yes I've got great faith in him, you know.

Patient T64

According to the medical records, the numbers of recorded encounters for individual patients during the year preceding interview varied from 4 to 166 (mean 33 encounters per patient). Just over half (18: 57%) were patient–practice encounters, of which 11 (40% of all encounters) were patient–GP encounters. There were no significant differences between sites in the overall numbers of practice encounters or GP encounters. The largest proportion of encounters occurred in the surgery and involved practice staff, including GPs (38%). Of these encounters at the surgery, 51% were for routine procedures (e.g. monitoring or bloods), although this figure was inflated by one patient who had 136 encounters for wound care. Other important encounter types directly involving patients were telephone calls between

surgery and patient (14%) and home visits (6%). Forty-three per cent were reviews in the absence of the patient. The remainder were largely the receipt of information from other organisations. Twenty-seven per cent of all records reported external reviews or treatment of the patient, 7% reported other information from other care providers and 3% reported discharge summaries. About 20% of the recorded patient contacts originated from secondary care teams and 14% originated from CHS. Unexpectedly, considering these patients' frailty, only 1% or fewer of encounters concerned each of the ambulance, out-of-hours or mental health services, a community hospital or community therapy [such as physiotherapists and occupational therapists (OTs)]. Only one encounter originated from a care agency and none originated from social services.

A care co-ordinator or case manager: cross-sectional continuity

There was little (if any) evidence of named care co-ordinators in the medical record (or, indeed, patient interviews). We therefore took two approaches to defining the de facto care co-ordinators. One rested on the criterion that the care co-ordinator is the person who initiates care (e.g. makes a referral). On this basis, care co-ordination was taking place in 12% of encounters and a care co-ordinator was identifiable (in at least some encounters) for most (89%) patients. GPs most often assumed the role (64% of all referrals), followed by hospital consultants (21%). Occasionally, practice staff, community nurses and therapists, podiatrists and other secondary practitioners such as hospital discharge teams assumed the role. Using this criterion there was a mean of 2.7 care co-ordinators per patient (range 0–10). The two common scenarios were patients whose GP was their main care co-ordinator (38%) and those who had no main care co-ordinator (i.e. no one individual responsible for the most referrals). One of the Whinshire general practices showed no evidence whatsoever of such a role. In three other practices (one each in Eastmere, Sedgeton and Tarrow) there was evidence of it for all sampled patients. This pattern did not vary significantly between sites.

An alternative criterion of being a care co-ordinator is someone who does more than just initiate care; for example, he or she seeks information, raises queries, acts as an advocate, chases up treatment and delegates tasks; or the patient seeks them out rather than looking for other sources of care. Using this criterion about 11% of patients' encounters involved care co-ordination. A mean of 1.7 individuals per patient were undertaking care co-ordination (range 0–8) and a care co-ordinator could be identified (on at least one encounter) for 73% of patients. The GP was the main care co-ordinator for 53% of patients and 28% had no identifiable care co-ordinator; secondary care was the only other substantial source of care co-ordination (8% of patients). These patterns did not significantly differ between study sites but did show significant variation at practice level, including considerable within-site variation.

Only 6% of patients had no care co-ordination using either definition. Most (66%) experienced care co-ordination of both forms. Consequently, a patient's care was typically being co-ordinated by several individuals (ranging from 0–9 with an average of 3.3, two of whom were typically GPs).

Our sample of patients did not recognise care co-ordination as such as valuable, but having one's own GP was appreciated, as other studies¹⁰⁵ have found. In each site a majority of patients felt that it was important to have someone responsible for co-ordinating their care as a whole, even if no one seemed to be doing so. Patients disliked the rule, reported in all sites, of dealing with just one problem per consultation:

I did see one doctor at that surgery and I said, 'Look, I don't come very often, I save up the few bits I want to ask'. And he said, 'That's no good, we only deal with one thing at the time,' and that was it.

Patient S50

Their records showed 59% of patients bringing more than one problem to at least one consultation. GPs often relaxed the rule, but if they applied it patients had to make repeat appointments and then would probably see different doctors, with the connections between problems possibly going unnoticed. One patient thought that this was why his diabetes had remained undiagnosed for a long time:

You are treated as two separate people: the person that's got the neurological problem and the person that's got everything else that's wrong with them [. . .] And many times I have said to both sides, 'I want to be treated as one patient, not as two separate patients'.

Patient W38

It also gave patients the problem of deciding which health issue to prioritise:

You seem to collect a myriad of problems [. . .] like a shopping list and they are all quite relevant, but you know if you were to go back for each one you would never be away from the doctors.

Patient S54

Patients seldom identified a case manager nurse as their care co-ordinator, although a few did identify nurses, in an undifferentiated way, as having that role. Frequency of contact led to familiarity, trust and the ability to discuss concerns. Having a de facto 'usual' doctor (see below) was associated with more wide-ranging consultations; 71% of patients with a usual GP had had at least one consultation (range 1–9) that covered more than one problem in the study period, compared with 29% of those without this relationship.

As far as they could tell, most patients at each site thought that the health workers caring for them seemed to work as a team. Equally, though, patients at every site described teamwork failures. Teamwork appeared to be stronger within the general practice and among the district nurses than between the hospital and either of these two primary care services:

Well, the GP end is pretty good. I mean, the GP, the various clinics and that that operate down there are fine. And the same as the hospital works. They just don't talk to each other.

Patient T057

The same person fulfils this role continuously: relational continuity

At all sites patients reported difficulty in seeing the same GP – particularly 'their' GP – at successive consultations.

Yeah, I go usually three times a year, about every 4 months and then you see one of the team [. . .] it's nearly always a different person.

Patient S55

Medical records showed that patients, on average (mode), saw four GPs in the preceding year (range 1–10). Patients divided almost equally between the 55% who saw the same GP at more than half of their encounters at the practice, and hence may be considered to have had a de facto 'designated' GP, and those who did not. Patients also saw, on average, two practice nurses and/or health-care assistants (range 0–6, mode 1). There were no significant differences between practices or sites in the mean number of GPs seen (range 3.3–6.0), but at both levels there was variation in the presence of a designated GP (ranging from 8% in Whinshire to 67% or more in Sedgeton, Tarrow and Eastmere). Patients were more likely to have a usual doctor in small or average size practices than in the larger ones (69% of sampled patients in Sedgeton and Tarrow had a usual GP compared with 27% in the latter).

Most patients (80%) wanted to see their 'own' doctor or case manager, especially about chronic morbidities:

[S]urely one doctor has got more interest in you than any Tom, Dick and Harry, as you might say.

Patient W37

Some patient–GP dyads made an effort to maintain continuity, despite obstacles. One GP asked a patient to come in for a check-up because of medication changes, but the patient then contacted her 'own' GP, who recorded 'can't get appointment with me so OK to have a month's worth and then review' (FMR25). Another patient in that practice managed to see his own GP on 16 out of 23 GP encounters (70%), despite the GP working only part-time. There were two systematic exceptions. Some patients focused not on whether they knew the GP but whether the GP knew them:

I'm not bothered about seeing the same doctor. They [GPs] have a weekly conference, get their heads together. They are familiar with my case.

Patient E03

The other exception was that when patients felt that they had an urgent problem (e.g. an exacerbation), they wanted swift access and were willing to 'take a chance on who you're getting' (patient S55).

Lack of relational continuity did not necessarily mean poor-quality interaction:

I have to say they were all absolutely gorgeous but there was no continuity. I saw a different person every time I went.

Patient E05

Telephone and e-mail were also partly replacing face-to-face contact. In the records we studied, telephone calls to or from the GP represented 14% of all encounters between the practice and the patient.

In Eastmere and Whinshire, especially, patients who had received hospital care often returned to the hospital doctor rather than go to the GP for advice on that problem:

No, because I thought if it's arthritic that's who I want to see, I want to see [consultant].

Patient W36

Access was direct; they felt 'able to query things' and 'just pick up the phone'. They then went only 'to see the GP for small ailments, the other ones I can go straight to the hospital' (patient W40). However, the medical records did not corroborate this pattern.

Most patients at every site said that they knew who was involved in caring for them. They were mostly clear about which nurses were involved and sometimes more vague about other health workers (therapists, etc.), which was especially true of patients with more complex conditions, including mental health problems. Patients were also confident that they knew which hospital staff were involved in their outpatient treatment and any post-discharge follow-up in the community, but less so about inpatient treatment.

A shared care plan or goal: longitudinal continuity

Care plans were notable mostly by their absence. In interviews, only 10% of patients were aware of a care plan or equivalent. GP records mentioned them in 25% of cases, although most of these would probably be more correctly designated treatment plans, and even these were absent in three of our study practices. Patients mostly valued the idea of care plans, although (perhaps revealingly) the term and concept were

unfamiliar. Yet most patients at each site perceived care plans as something that other people might need (e.g. patients less fit than themselves), as something to do with social care, or even as a diversion from actual care:

I would rather just have the care, you know. Never mind about the plan.

Patient S45

As only a minority were aware of having a care plan, most were unaware of what their care plan was. Some assumed that their GP had probably made one:

I don't know as they've really gone into that, I mean, I'm sure that must be part and parcel of their job as a doctor, isn't it, to look after your interests?

Patient S55

Others suspected that they had no care plan, although felt that one would improve their care:

I'd love to have a proper plan. Because that would mean the consultant and the doctor [GP] would have to talk to one another. And that's the bit that doesn't happen.

Patient W38

If care or treatment plans did exist, they tended to be produced by the separate providers, so that a patient with multiple providers might end up with multiple partial care plans but still no overall plan:

The company that provide the service for me, they've got their plan. And [voluntary mental health care provider] have got their care plan, such as it is. And the district nurses, all the folders are in that corner, the district nurses have got their plan. But I'm not aware, in fact I'm sure there's not, a similar, overall – that's why I say that it would be good to know that there was someone who could and would co-ordinate all these things [. . .] It may be that [GP] does know these things, but I'm not aware that he does.

Patient T068

From our study general practices, 51% of GP referrals were to secondary care and only 34% to CHS. Patients often blamed slow access to secondary care on the hospital, sometimes correctly as this GP's letter to a consultant illustrated:

Curiously you have asked me as a GP to arrange this [update MRI scan . . .] I do not see it as the role of the GP to organise the investigations requested by a secondary care specialist service [. . .] I am unaware that there have been any changes in imaging policies in [place]. The patient came in today very confused and concerned about the delay. Please expedite organising the investigations you wish to be done [. . .] then arrange your follow up appointment to discuss the results with him in the usual manner.

SMR55

Of the patients who had spent time in hospital in the last year, only 40% agreed that their care had been followed up after discharge, with shortfalls reported at every site. Patients tended to dislike what they regarded as premature discharge, hospitals' tendency to leave post-discharge arrangements to other organisations, time-limited follow-up care or, worse, being 'abandoned' after discharge. This patient thought that post-discharge care 'should mean at least one visit from somebody in the practice, if not a doctor then certainly a practice nurse' (patient F17). However, the requisite follow-up involved district nursing as often as general practice care. Interestingly, patients noticed a difference between follow-up for common treatments (e.g. hip replacement) where a support package would automatically follow

['Oh yes, I think they have to, I think isn't it about 6 weeks; I believe that's what it is' (patient S49)] and less common immobilising illnesses where no such support was offered. Some patients, therefore, had quite a positive experience of post-discharge care:

Well, the day after I got back a woman appeared at the door there and it turned out she was a nurse and I said well I haven't asked for any help. She said this is, oh something they are doing free. Short-term . . . Short-term enablement.

Patient E011

The experience could also be positive with regard to prompting home assessments for the inspection of beds, flooring and the need for equipment or catheters. In these cases it was clear that the hospital had triggered help in the community.

Reviews of the patient's circumstances: flexible continuity

About one-third of all patients said that their care was regularly and frequently reviewed, although 44% said that it was not reviewed regularly (or, in some cases, at all). At one extreme:

I suppose the longest between interviews would be about 2 months, but in practice it's quite a bit closer than that really. It tends to vary. If I carry on, the communication, [it's] because I think [GP] . . . she takes proper account of that and tries to see that everything is dealt with that should be.

Patient E04

At the other extreme, patients felt that they had to initiate any such review:

I have very high blood pressure which is a problem but I only get my blood pressure checked if I make an appointment . . . and that applies to a lot of the things, like I should have my thyroid checked every year, I should have . . . I have pernicious anaemia, I think I should have my B12 levels checked.

Patient S54

In the medical records, 24% of items were recalls, timetabled for up to a year ahead (although many of these related to seemingly acute conditions, such as ongoing wound care, which could necessitate multiple trips into the surgery. Many also related to recall for a single condition only). Additionally, 8% of encounters showed evidence of review (e.g. a wide-ranging consultation or a note to review at home). In that sense all but 9% of patients had been reviewed at some stage during the previous year, with little variation between areas or practices. Patients valued regular care reviews for giving reassurance, especially as they got older. Some care reviews (e.g. for diabetes) were routine, carried out by practice nurses and seemed superficial to some patients owing to being condition specific and not reviewing their health in the round. A GP's response to changes in the patient's circumstances tended to inspire confidence:

[T]hey do check on something like that and they will follow up on it, they'll call you back or you'll get a letter, a phone call and they'll ask you to come down for another test or something like that, so they're pretty good about that.

Patient W36

Patients also sometimes described themselves as prompting a 'review' of their care after their condition deteriorated, but that meant the patient initiating a new episode of care rather than routine, active health monitoring by a health worker. About 43% of medical record entries reported GP (chiefly medication) reviews in the absence of the patient, of which patients would mostly have been unaware. Overall, only one patient had had no reviews when the three measures (GP recall, evidence of review and medication review) were taken together.

Interruptions, gaps to care, missing services, changes of provider: access continuity

The most often reported threat to continuity of access was insufficient time with the GP (also reported in other studies¹⁰⁵), so that the patient felt 'akin to being on a conveyor belt' (patient W38) with too little time to explain their overall condition, reinforcing the effect of the one-condition-per-consultation rule in jeopardising cross-sectional continuity of care:

[GP name] was the only person who seemed to hassle me. And in the end I said to him, 'Look, if you haven't got time I'll leave'. And the average patient possibly wouldn't have dared.

Patient F24

Patients often found that GP appointment (e.g. 'book on the day') systems impeded access to the general practice. One patient always went to the surgery to make non-emergency appointments:

First of all, they never pick the phone up; secondly, I think they make more effort to look if you're there.

Patient S50

Patients also perceived lack of time as reducing other health workers' ability to show interest and pay individual attention to the patient.

Only 1% or 2%, respectively, of events in the medical records concerned mental health services as the originator or destination of a referral, which may explain why patients so rarely mentioned mental health services in their interviews. Yet in contrast, 23% of patients referred to their mental health problems, most commonly depression but also schizophrenia, Alzheimer's, dementia, loss of memory, panic disorder and anxiety. Even fewer recorded encounters that originated from or resulted in contact with social care, but this may reflect low levels of social worker communication with GPs rather than lack of social care itself. As noted, only 14% of the interviewees were currently receiving a care package.

Medical records also suggested that levels of engagement with CHS varied significantly between sites. Only 33% of patients in Fivecastles had any such input (and levels in Whinshire were also below the sample average), whereas all patients in Sedgeton and the majority in Eastmere and Tarrow had it. Patients commonly reported that district nursing teams rigidly applied the 'housebound' criterion of needing to receive services at home and were prompt to cease providing services. One patient in his nineties and prone to falls found district nurse support withdrawn because he had gone to the corner shop for milk on his mobility scooter. The same happened to another who, using a walking frame, was able to struggle into the surgery by taking a taxi to the bus stop.

Transfer of information and records: informational continuity

In the medical records, good information transfer and utilisation (copying other care providers and the patient into communications; providing contextual information) were noted more frequently (8% of patient records) than explicit records of missing information (3%), for example 'there are no notes available to me' (E10). Between one-quarter and half of patients at every site described instances of information about their diagnosis, history or treatment not being passed between providers. In every site, patients reported correcting health worker omissions and out-of-date information. Patients often had to recapitulate information to the next GP or other health worker who saw them. For example, where a district general hospital (DGH) had not acted on an urgent GP referral, the patient was admitted as an emergency 2 days later, partly because 'the protocol for handling things like fax hadn't really been

established' (patient F17) and partly because of individual errors, for instance a medical secretary 'hadn't appreciated that it was urgent, or that she had some role in making urgent appointments' (patient F17) or lack of staff time (e.g. to read the notes before seeing the patient). Patients thought that information transfers between general practices and hospitals were less reliable than transfers within their general practice or between non-hospital services:

The only thing I'd say that could be improved is the communications between the local GP and the hospital. There seems quite a lapse between [going] there and getting the results don't there?

Patient T60

Paper notes or records kept at the patient's home often served as a common information source for any staff making home visits. Some patients carried their own medical histories in an attempt to compensate for system failures and reduce the pressure on them to be conduits of information when vulnerable and ill.

From the medical records we also extracted data about information flows (i.e. reports of reviews and meetings, treatment or other information or advice) between providers. Overall, 34% of encounters related to such information transfer. Information transfers were recorded for all but three patients. However, there were significant differences between sites (and practices) in the number of information transfers recorded for each patient. Three study areas (Whinshire, Sedgeton and Eastmere) all recorded similar, above average levels of information flow (10–11 exchanges per patient). Tarrow had only about half the numbers of information transfers recorded in other areas.

Patient contribution to self-care and decision-making

Patients identified the general practice (40%) and themselves or their family (37%) as having the best overview of their care. Patients ranged from those who took the initiative (e.g. reading about their condition before going to the GP) to those who passively trusted the professionals and those who unilaterally altered treatments that others had arranged. Their medical records showed that 45% of patients had acted as their own care co-ordinator on at least one encounter. Some patients actively chased up appointments, made contact with service providers, offered information and decided whether or not to pursue treatment options.

Forty-one per cent of patients' medical records showed some form of patient resistance to the care provided during the past year, ranging from those who felt they knew their body best and were 'perfectly prepared to disregard doctors' instructions' if they 'thought it necessary' (S45), to those who because of frailty or terminal illnesses no longer wanted active interventions, and those who did not access the service offered because the barriers they had to overcome were too great.

People might become an expert patient or carer by default because they thought that the services they had encountered lacked knowledge, variously, of their condition, of the correct diagnoses and attribution of problems, of appropriate treatment and care (e.g. knowing why a patient needed to wear gloves) and of the necessity for referral to another specialty. A friend had advised one patient to 'learn as much as you can about your own illness – as you will encounter doctors and nurses who don't' (patient W32).

Not all of these patients were happy co-ordinating their own care:

I have to now push to get diabetic appointments, push to get doctor appointments, push to see my consultant; that's not right. I shouldn't be the one that has to be proactive; it should be them calling me in.

Patient W38

These individual responses seemed partly to reflect personality:

I don't like somebody coming and taking a test of something, even if it's only giving me an injection, I need to know what it's for, I need to know why they're doing it and I need to know whether I could do without it. It's got on my notes at the hospital, 'This lady needs to know everything'.

Patient F20

However, the responses might also reflect the patients' state of health. On occasion patients experienced difficulty in filling their assigned roles, for example recalling information or accessing counselling. One patient had tried referring himself to the bereavement service CRUSE, but was put off by the condition of others seeking help and asked himself ' "Do I want to go in here?" I thought, "No" . . . so I left it' (patient S48).

The responses also reflected a lack of available or known options; one patient without family and who used two crutches organised a removal company to facilitate his discharge while he was in hospital following a fall:

[A]nd of course I was so keen to go home, I was doing everything I could, and I'd had to ring up some furniture removers to take away a big settee that was here and bring my bed downstairs, the little guest bed.

Patient F19

A persistent theme was that vulnerable patients could easily be put off seeking help by a variety of seemingly small factors that together defeated them. Some felt that their problems were not significant enough, particularly if they expected that the GP would think so, too. However, comparing their interviews with their medical records, patients tended, if anything, to underestimate their health problems.

Patients at all sites depended on their spouses, other family members or wider social networks to provide additional care, 'good friends bless them' (patient E02), and help them access health services. Levels of informal support varied considerably. Many patients thought that they should not be overdemanding:

Well honestly, not being funny, it's the way you've been brought up. Because I mean half the time I wouldn't have gone to the hospital about anything you know.

Patient W42

To varying extents across the sites, a minority of patients used private health services.

Differences in patient experiences of continuities of care across sites

The differences between patients' experiences of continuities of care across the study general practices were fewer than the similarities.

Different experiences of general practices and other first responders

Two main differences across sites appeared to be in regard to patients' experiences of general practices and to other first responders.

Although patients everywhere reported difficulty in seeing the same GP, that appeared to be particularly difficult in the corporate general practice. As far as patients could ascertain, it had no full-time GPs, with the part-time core staff being supplemented by trainees and locums.

Now we have three main doctors and a lot of doctors who come in one a day or this day or that day [. . .] they are both very considerate and very efficient and effective. But trying to get an appointment with them is extremely difficult.

Patient F20

Patients explained:

[GP name] himself is only there on Mondays and he's got a partner who manages the general practice as a business, they've got more than one surgery and he's only there 1 day a week.

Patient F15

They run their practices very much more as a business than they used to [. . .] they certainly don't want to overstaff the practice with more doctors than necessary, so obviously it becomes a little bit more difficult to get an appointment.

Patient F24

The medical records also indicated significant differences between professional partnerships in the proportion of patients seeing a 'designated' GP (see p. 43): 8% in Whinshire versus 67% or more in Sedgeton, Tarrow and Eastmere.

Concomitantly, although GPs dealt with patients mostly through appointments at the surgery or by telephone, there were significant differences in willingness to undertake home visits. Overall, 5% of encounters recorded in the medical records were GP home visits. This ranged from 1.6% in the corporate general practice to 8.3% in one of the more rural and dispersed study sites, where GPs still did make home visits to their patients. However, three professional partnership general practices recorded no home visits at all.

Patients also noticed that the corporate general practice often sent them pharmacological recommendations to change their medication. Mostly, patients felt that this surgery was thorough, up to date and efficient, with good information systems and GP records, and that it was 'very good at checking things out. And I assume, and I think I'm right in assuming, that the hospital's treatment gets advised back to the surgery and they're kept' (patient F21).

The medical records did not necessarily corroborate this impression. As noted, the quantity of recorded information flows on record was below average in Fivecastles, which was one of the three areas with an above-average incidence of poor information transfer.

Another difference between sites was that patients in Fivecastles and Sedgeton hardly commented on the idea of bypassing general practice for care reviews or queries, mentioning only standard recalls for urology and cardiology, for example, whereas in Eastmere and Whinshire patients maintained direct contact with the hospital in the event of exacerbations: 'Well [the heart specialist] told me to ring there, his office, if I get serious problems' (patient W40).

Different experiences of interorganisational co-ordination

In Fivecastles, patients' experiences of transfers to other providers appeared to differ in two ways from the other study general practices. Fivecastles patients engaged mostly with the general practice or hospital and less so with a larger primary care network. CHS involvement was significantly lower (recorded for only 33% of sample patients) than in other sites (100% in Sedgeton). Furthermore, the Fivecastles practice seemed very willing to refer patients for NHS-funded treatment by private providers, including private diagnostic and treatment centres, but also to other private providers. Our study patients did not mention any of the other facilities in the county owned by the same company.

Patients at different sites reported contrasting experiences of their general practices' willingness to refer them as private-payer patients to private health-care providers. The Fivecastles general practice readily did so. Several patients had GP referrals for private treatments at the DGH, local hospitals and London private hospitals, especially for cardiology and conditions such as a brain cyst where rapid treatment seemed

important. Even one patient in social housing ‘went private’ after NHS providers were slow to diagnose a twisted gut. The Sedgeton general practices did not facilitate such referrals:

[I]f I have not heard in a few weeks’ time I shall make my own arrangements . . . I’ve never found a doctor who’d refer me privately, even though you say, ‘I’m happy to be referred privately’.

Patient S45

Nor were the study practices in Whinshire, Eastmere and Tarrow very active in referring patients for privately funded treatment. Patients in the Fivecastles sample were three times more likely than the study average to be referred to a non-NHS provider or to be treated privately. Patients in Whinshire (and Sedgeton) reported waiting several times longer than the NHS national target for secondary care.

Different experiences of ‘second-responder’ care co-ordination

Patients in Fivecastles described a certain freedom of movement between CHS and hospital care. After discharge to CHS, they were able to return to the DGH for a limited time period without needing further referrals, although one talked of the difficulty even then of getting more than one thing done at a time (e.g. blood tests while in hospital, the lack of which would have necessitated a return to primary care if he had been less assertive). In the same way, patients could access the day hospital, which they praised for its holistic approach:

[T]hey also look at your diet, they look at all aspects of your present living. You know, I mean there’s a whole team of nurses there and there’s a resident doctor.

Patient F26

This ‘one-stop shop’ gave access to physiotherapy and occupational therapy as a minimum, together with access to speech and language therapists, dieticians, nurses and geriatricians.

Whinshire patients were the only group describing unreliable hospital-to-hospital information transfer, and this was the only study site to refer patients consistently to two DGHs:

I got a letter from the haematologist at [town], she wanted me to see a neurologist and I’ve got the letter that she sent to my doctor saying she’s had no information from the [other town] neurologist.

Patient W42

A haematologist wrote:

[I] understand [patient] was seen by a neurologist at [other DGH] in order to investigate further funny turns: Unfortunately, I have received no correspondence whatsoever from [other DGH] and am at loss to understand exactly what is going on. [Patient] tells me [neurologist] does not think TIAs and has been put on a reveal cardiac monitor. I would be very grateful if [other DGH] consultants could copy me in on their clinic letters.

WMR42

In summary, the main similarities in patient experiences across our study sites were:

1. GPs were the main de facto care co-ordinator.
2. Few patients had designated care co-ordinators.
3. The one-item-per-consultation rule was seen as impeding holistic care.
4. Overall care plans existed for only a minority of patients (even in this frail care group).
5. Relational continuity was patchy.
6. Telephone contact with the GP was partly replacing face-to-face contact.
7. Nearly half of the patients had no regular reviews.
8. Patients reported having little time with the GP.

Differences were:

1. In Fivecastles and Whinshire we found:
 - i. lower perceived relational continuity with the GPs
 - ii. fewer home visits, especially compared with Eastmere
 - iii. lower levels of engagement with CHS, especially compared with Sedgeton.
2. Higher use of private providers in Fivecastles.
3. Care co-ordination conducted predominantly by the general practice in Eastmere and Tarrow, with more mixed responsibility in Sedgeton, Fivecastles and Whinshire.
4. Lower levels of recorded information in Fivecastles and Tarrow, but apparently good use of IT systems in Fivecastles.

Chapter 6 Care co-ordination in general practice

Explaining patients' experience at general practice level

Next, we consider which co-ordination mechanisms were present or absent within the first-responder provider organisations, and compare these mechanisms with the patterns of patient experience reported in *Chapter 5*. This will enable us to consider to what extent the latter may explain the former.

Commonalities across the general practices

Care co-ordinator

The patients we interviewed usually felt that they knew where to seek additional health care and that it was from a GP, preferably their 'usual' GP. Few of them, however, were aware of having a designated care co-ordinator, an impression that their medical records confirmed. Nevertheless, GPs in our study practice believed both that being a care co-ordinator was the proper, normal role for a GP – 'You are always a case manager for the patient you are seeing at any one time' (GP WP01) – and that GPs were best qualified for it:

We need to take a more doctor-centred approach to chronic disease management. The nurses are good but if e.g. [they] follow diabetic protocol – such patients will inevitably also be hypertensive and have chronic artery disease (CAD). A GP appointment may not be so cuddly or client friendly but it does deal with the whole smorgasbord.

GP WP01

Frequently GPs' co-ordinator role was tacit rather than openly discussed. GPs would be care co-ordinator by default when patients did not fit neatly into any other category with special care co-ordination arrangements.

For particular classes of patients, having a named GP with specific care co-ordination responsibilities was becoming more common. For example, one of the Eastmere practices had a named GP for each cancer patient. The corporate general practice had a flagged list of vulnerable patients for whom the receptionists were told to allow ready access to the GPs. Some general practices (Eastmere, Tarrow and Whinshire and briefly, but financially unsuccessfully, Fivecastles) provided personalised care by in-reach into nursing homes, with each nursing home having a responsible GP (Eastmere) and/or with one GP responsible for all nursing homes with which their practice dealt (Whinshire and Tarrow). When patients entered a nursing home, their 'usual' GP might or, more often, might not be the one in charge of their care. In one Tarrow practice, the GP(s) who had previously provided services to the nursing home continued to provide those aspects of care not covered by the General Medical Services (GMS) contract. Practices did not always have the option to provide GP cover for community hospitals (as in Eastmere). Although GPs valued their care co-ordinator role, they were content to delegate some of it to, for example, community matrons, advanced nurse practitioners (ANPs) or other external care co-ordinators (see *Chapter 7*) for some patients at the top of the Wagner pyramid. However, these were only a minority of their older frail patients.

Against this, the changes to the division of general practice labour described below were reducing relational continuity of care for the other patients.

Care plans

One reason why care plans were not very visible to patients (see *Chapter 5*) was that few had them. In the general practices we studied, this was because GPs were cautious or guarded about the relevance and utility of care plans, and because of the time required to produce and update them (and 'Health Passports'). There was also insufficient time to encourage care planning more generally at practice level.

Indeed, one GP suggested that written care plans were not a GP function (rather, they were a focus for nursing care, and not required if a good reactive system was in place). As with the care co-ordination role, nursing and care home residents were something of an exception. In Tarrow and in part of Eastmere, GPs' coverage of whole nursing homes aimed to create integrated care plans and give standard weekly 'ward round'-like medical care. In Eastmere, these personalised care plans were being piloted for every dementia patient on the Quality and Outcomes Framework (QOF) register in two general practices and:

every [. . .] nursing home and residential home bed [. . .] mainly around end-of-life care and anticipatory care plans as well as medication reviews.

GP EP19

There, and in Tarrow, these patients would get a care plan within 1 day of admission to a nursing home; their care plans would always be reviewed on hospital admission and discharge, and the nursing home GP became recognised as a GPSI-like expert in that activity.

Of our patient sample, 56% were aware of having their care reviewed regularly (if infrequently, for some). For those for whom this happened, our general practice informants told us that care reviews were made by recall, a home visit, a telephone call to the patient or a practice meeting (without the patient present). On occasion, selected patients were also the subject of a case meeting or MDT meeting. GPs' review and recall processes (e.g. medication reviews) were driven largely by QOF targets:

I think QOF has worked very well, you know, in terms of people actually getting their checks. And an awareness of targets and, you know, management of diabetes.

Community team lead SP06

Or, more guardedly:

There are some useful things about QOF – it does flag things to be done – but some are utterly meaningless.

GP WP01

Among the meaningless things, this GP counted the depression questionnaire. Practice nurses did much of the routine monitoring, especially for QOF (annual reviews for COPD and diabetes). These were the care reviews that some patients found 'superficial' and did not count as overall reviews of their care. However, many of the study general practices went beyond what QOF required. In Tarrow, for example, one of our study general practices regularly monitored patients with arthritis (a condition not included in QOF until 2013). Regular GP visits to nursing homes were an opportunity for care review, and were becoming more common for housebound patients, too (e.g. in Tarrow). Care reviews were also sometimes made opportunistically when GPs responded to changes in a patient's circumstances (e.g. in Eastmere). Reviews were also made at the instigation of a multiagency (care network) team.

The corporate general practice had protocols for how often patients' care should be reviewed, depending on the patient's condition and treatment, and it used the whitelist described above. A senior GP regularly led audits of condition prevalence and follow-up. This was explained as a necessary response to early discharge and the delegation of follow-up to primary care:

Because obviously patients do not tend to be kept on for outpatient appointments quite like they were, they tend to be discharged back to primary care now. So there is that concern about are we recalling these patients and keeping an eye on them. And we did find actually that there were definitely a few patients that were not being followed up as well as they should have been. So those sorts of processes can be quite useful.

GP P03

Partly this was driven by QOF and the CCG's emphasis on audit, but some were 'driven by a significant event that gets flagged up and we look at it and we think actually, you know, this is an opportunity to learn' (GP FP03).

Our patient interviewees, however, often described the lack of follow-up or review by their general practice after they were discharged from hospital. Only in one of our five study areas did more than half of eligible respondents agree that they had been checked up on once back at home.

The uneven coverage of care reviews at the individual level thus appeared to reflect:

- single-condition reviews being given as mandated by QOF
- general practices using their own discretion in deciding when to do more care reviewing than this
- our inference that, as GPs thought care planning was laborious and of limited utility (see above), the same thinking applied to formal care reviews (a corollary of care planning).

Continuity of access: missing and extra services

Our patient interviewees cogently described their experiences of the one-item-per-consultation rule, irregular continuity of contact with their 'own' GP, little time with the GP and the role of telephone contact and triage. One immediate explanation was heavy and increasing GP workloads. Care co-ordination of older people with complex needs was only one – and not necessarily the biggest – cause. GPs also faced demands for quick appointment times. Workload pressures on GPs were manifested in:

1. The one-problem-per-consultation rule, which reduced cross-sectional continuity, although as noted GPs did not apply it rigidly. GPs at one study practice in Eastmere actively checked about patients' earlier problems when they presented with new ones and maintained high relational continuity with these patients. In one of our Whinshire study practices, urgent appointments were for one issue only but 'by negotiation' several might be dealt with at other times. This was an evident source of tension for GPs as well as patients. One patient's medical notes recorded that the one-problem-per-appointment rule was explained, but the patient had 'unrealistic expectations about what can be safely managed in 10 minutes . . . [and] about being symptom free as she ages' (SMR43).
2. Disinclination to provide 'extended hours' services. Patients who needed such services, therefore, had to use the separate out-of-hours service, ambulance or ED, reducing longitudinal continuity of care.
3. Practice lists of patients were generally replacing personal lists, so that responsibility for each patient was shared across the whole practice instead of each patient having a named GP. However, one of our Sedgeton practices did still operate personal lists and in others patients had a named 'usual' doctor. In one of our Tarrow study practices, medical records showed that the patient's usual doctor made the home visit even if another GP had taken the telephone call that triggered it. Like their patients, our study GPs noticed the reduced relational continuity of care.

[W]e don't have personalised lists which is a real shame . . . We don't have time to do the things that make general practice good any more. We don't have time for [. . .] domiciliary visits any more. . . that popping in doesn't exist any more.

GP EP19

Over the years you develop a long-term relationship and they consider you 'their doctor'. But I can't deliver a personal service – the pressure on appointments is too much.

GP WP01

4. Restricted capacity to add services to the general practice (Whinshire) or to contribute to the meetings and service development activity of care network co-ordinating bodies (see *Chapter 8*). One of our study GPs had reduced his hours at his own general practice in order to assume a CCG role, something that the practice did not appreciate.

5. Use of medical labour-saving techniques such as telephone and e-mail consultations, and employing non-medical clinicians to do such work as QOF-based care reviews (and often more work than this).
6. In Eastmere and Fivecastles, both patients and health workers described receptionists as barriers to patients', and even ANPs', access to the GPs.

The study general practices' additions of new services and specialisations reflected the GPs' personal background and interests. Thus, both of the Whinshire study general practices offered minor surgery, to that extent substituting for hospital treatment. One practice had also developed further services for procedures that otherwise would have required a referral to hospital or treatment centre (e.g. spirometry, electrocardiograms and 24-hour blood-pressure monitoring). Another general practice in Whinshire had recruited a GP with a cardiology specialism, but not as a GPSI because of the cost. The presence of specialised GPs encouraged the recruitment of patients and resulted in a better service for them, but also tended to create more clinical and care coordination work in treating patients with complex care needs, because if a specialised GP was present the other GPs tended to use them. Similarly, the GPs felt that a NP worked in effect like a GP, creating their own workload and pulling patients into the practice.

Like others of their kind,²⁵⁶ the professional partnership practices employed NPs, practice nurses, health-care assistants and phlebotomists. The small corporate general practice had the lowest number of support staff; they had a part-time phlebotomist and the practice nurse, but they also had a pharmacist who conducted medication reviews, an unusual occurrence in a non-dispensing practice and, effectively, a delegation of responsibility for signing off scripts. Because the pharmacist 'knows a lot of the patients from being behind the counter at the chemist' (GP FP03), this arrangement was also 'able to give [the GPs] a different perspective on what's going on with [the patients], you know, whether they're remembering to take their medication, who's picking up their medication' (GP FP03). The post was funded by savings from the prescription budget. GPs might also have a clinical interest in working with older people with complex needs. For instance:

What's required, I think, move common ailments and health advice and the, sort of, end of my job which I do which I don't necessarily have to have had the degree of training that I've had to do it, taken away from me, giving me more time to spend with the frail.

GP SP10

In some instances where new services were being introduced (Eastmere), we found that, although GPs were contracted to provide the CCG with outcome indicator data for evaluating a new project, they were uninterested in doing so even though they would be paid for it:

The requirement to provide outcome data had been written into contracts by the CCG but GPs are saying, 'No, can't do it, don't want to do it even for the money'. And I can only see that getting worse.

GP EP19

Heavy workloads had neutralised financial incentives at the margin. GPs' personal interests might also orient their general practices towards expanding their income, increasing the range of practice activities accordingly. One of our study GPs, for example, had set up a private company in parallel with his general practice.

Internal care co-ordination

Over one-fifth of our sampled patients felt unable to assess whether or not the people looking after them worked well as a team, but most of those responding (77%) thought that co-ordination ('teamwork') was evident. Many cited their general practice as evidence. Another general practice response to increasing workload was to delegate more of it to practice nurses, who ran many review clinics (e.g. diabetes, asthma/COPD control), did some care planning, provided routine health checks, managed common ailments and gave health advice. At one of our Sedgeton study practices, the practice nurse acted as case manager for MDT patients, reviewing their care at a home visit and putting them in touch with appropriate services, although we were told that this arrangement did not work well for patients with

mental health problems. Salaried employment of one GP by others (practice partners) or by a corporation is also becoming more common.¹⁹ This study included instances of both arrangements.

The GPs held practice-level 'team' meetings to deal inter alia with care co-ordination matters, especially expected hospital admissions or discharges for patients with complex needs, as well as to handle referrals. One of the Eastmere general practices held fortnightly hospital discharge meetings to discuss elderly frail patients and ensure that they were contacted and followed up. We were told that this is becoming more common as patients are being discharged with more tasks back to primary care. Both study general practices in Whinshire held formal weekly meetings (which also covered clinical teaching) as well as ad-hoc informal discussions, often daily:

[W]e have particularly good relationships between the partners and always discuss patients. We have what we call the 'flight-deck' with six computers and a big table where we congregate on an informal basis and bounce decisions.

GP WP01

Similarly, in the corporate general practice, the GPs, in-house pharmacist, administrator and practice manager also met weekly to manage referrals and to support locums and trainees:

[W]e can talk through whether a referral is legitimate or whether it's something that we can sort out in house [. . .] I think it probably works well because we're a small practice so, you know, there aren't too many people at the meeting and we all do get on very well as a team.

GP FP03

Some, but not all, of the (internal) team meetings in the other study practices also involved a designated receptionist, district nurse and ANP with the designated GP (i.e. practice employees besides the GP partners, their employers) to discuss patients with multiple complex needs.

The study practices also hosted meetings for, and their GPs participated in, interorganisational primary care teams (see *Chapter 8*).

General practitioners in the study general practices made efforts to share information (in addition to patient records) with each other. This had been formalised especially in our Fivecastles study practice as their strategy for compensating for a fragmented GP workforce. Part-time salaried working is becoming more common among English GPs, and so this information-sharing culture seems to reflect a more general imperative. Practice IT systems were always substantially computerised. Staff in both Eastmere general practices, for example, talked of good communication and records. However, to varying extents, general practice information systems were also administratively closed to, and technically not interoperable with, other providers' or care networks' health records systems. The data available to the Eastmere CCG were reported as being 'extremely poor' (EP19). Partly this closure might have been because GPs anticipated, or had already experienced, that having too much information about a patient 'clogs up the record and leaves us [GPs] to cut the wheat from the chaff' (GP WP02).

This GP found that, as a consequence, it was becoming harder to spot the important action points quickly, which might raise risk management issues. Nevertheless, general practice information systems were gradually becoming more accessible to external health-care providers (see *Chapter 5*).

Despite all the above expedients, general practice resources were simply too small in scale and narrow in range to provide all the care that patients with complex health problems needed at home or in a community hospital. One GP saw organisational integration of a wider range of services within his general practice as an ideal 'Oh, my dream . . . I would love us to hire our own district nurse, health visitor, mental health nurse' (GP EP19).

Referral to additional providers, and the ensuing care co-ordination, still took place by default through the consultation model. GPs had a monopoly on some referrals and authorisations to providers outside their general practice, in particular to consultants. Post-discharge hand-back of the patient from consultant to GP was usually immediate, but in one of the Tarrow virtual wards (see *Chapter 8*) the consultant retained responsibility for patients.

Differences in care co-ordination across the study general practices

A corporate general practice

Some of our patient interviews had noticed, and speculated about, the biggest organisational difference among our study general practices: that one of them was owned by a corporation that owned and ran other general practices and other health services. In that study site, corporate ownership appeared to have three main consequences for co-ordinating the care of people with complex care needs:

1. Because the doctors also worked elsewhere, each made only small inputs to this practice, resulting, as their patients noticed (see *Chapter 7*) and the GPs acknowledged, in low personal continuity of care. Its well-developed IT system (on which patients remarked) was in part a compensatory mechanism to produce at least some longitudinal continuity of care. There were also, as patients had again noticed, few home visits.
2. Two doctors were accountable to the third, who had wider clinical management responsibilities across the company.
3. The company provided other services in the locality. An ophthalmology clinic owned by the same corporation was on the floor above the study general practice, but run completely separately (although the practice's doctors could refer to it). Contrariwise, patients at a nearby community hospital had received services from the corporation's doctors rather than their own GPs, many of whom worked in the (independent) general practice across the road. Furthermore, the corporation reportedly sent different doctors each day of the week. The company had also taken over some local care homes and used its doctors to provide and co-ordinate care there, although that project had been discontinued partly for financial reasons. Our study practice had once hosted private physiotherapy and chiropractor services, but was too small to host a NHS physiotherapist or to exploit the easy links to additional services that could, in theory, have resulted from being part of a wider organisation. It thus appeared little different from other nearby general practices in terms of its patients' access to other services run by the company – an unexpected finding.

Professional partnership general practices also have made certain other innovations that the corporate general practice pursued.²⁵⁶ It recruited an in-house pharmacist, which released doctors from the reviews associated with signing off requests for prescriptions to do other work, and readily referred patients to private diagnostic services. It was not obvious to us whether readiness to refer to private providers of diagnostic services reflected its corporate ownership, small size or normal referral patterns in that CCG. In addition, the corporate study practice had a whitelist of patients who were allowed easy access to the GP:

[I]f a patient rings up [and] that name means something to [the reception team] and they will make sure that they give them an urgent appointment [because . . .] what you want to be sure you're not missing are the people who do not like bothering the doctor but, you know, are quietly sitting at home and not doing very well.

GP FP03

In such a small general practice, ownership seemed to have less influence than organisational size on care co-ordination; in most aspects of care co-ordination except those indicated above, the corporate general practice was similar to the professional partnerships.

Integrated information systems

In Whinshire, some general practices used shared medical records to which health and social care staff of other organisations, besides GPs and general practice staff, had read–write access. The Sedgeton general practices had an urgent clinical care ‘dashboard’ that, as part of the local anticipatory planning process introduced by the integrated primary care teams (IPCTs) (see *Appendix 5*), could be used to highlight patients whose needs or service use were increasing. They planned to give the out-of-hours and the ambulance services real-time access to it, and to include care plans on it, but at the time of our fieldwork these additions had not yet been implemented.

Other first responders

It was noticeable how little the patients we interviewed mentioned out-of-hours services, in whose use there was a marked decline nationally during the period of our fieldwork.¹⁷ In Eastmere, out-of-hours medical cover was simply scarce. In contrast, EDs faced increasing demand. The care networks described below responded in Sedgeton and Whinshire by introducing ‘front-door’ teams to triage incoming patients with complex conditions, so as to divert (i.e. refer on) those whose condition allowed it to other providers. The care network co-ordinating bodies (‘hubs’) in Eastmere and Sedgeton also accepted self-referrals, but as their main role was care network co-ordination (routing or diverting referrals originating from other provider organisations), we describe them in *Chapter 8*.

Comparison of patient experiences with care co-ordination mechanisms in general practices

To the extent reported above, the care co-ordination mechanisms, or the absence of them, found in the study general practices matched, and hence explained, the patient experiences reported in *Chapter 5*. There remain three ways in which they did not match.

Organisation-level co-ordination structures invisible to the patient

Some co-ordination mechanisms were, for patients, behind the scenes. Patients might notice the effects but not the co-ordination mechanism itself. Thus, some case conferences (or equivalents) and care reviews involved only general practice staff and not the patients, who were not always aware that these were taking place. Patients knew that non-doctors at the practice provided, and even co-ordinated, some of their care, but had neither occasion nor reason to know what line-management arrangements achieved this; nor, similarly, what information systems transmitted (or lost) information. With our patient sample, it so happened that few had used the additional (e.g. minor surgery) or colocated (e.g. mental health support) services that some of the study general practices provided.

Non-organisational influences on care co-ordination

Some aspects of patient experience of care co-ordination had obviously non-organisational explanations: patients liking to have their ‘own’ GP; whether patients took the initiative in co-ordinating their own care, passively complied with or resisted health workers’ initiatives; and what personal capacities and resources, including their state of health, patients brought to their care. GPs’ own backgrounds and interests also influenced how care was co-ordinated and what resources were available for it.

Higher-level constraints on care co-ordination

At health-system governance level, the contractual and QOF framework in which GPs worked, CCG imperatives and national policy and guidance were all reflected in GP workloads and priorities. More immediate external constraints on general practices' co-ordination of patients' care were as follows:

1. availability of budgets or payments for additional care co-ordination work
2. the presence and scope of multiagency teams to provide access to services that general practices did not provide
3. the availability of external providers willing to provide additional services on general practice premises
4. the openness or closure of other providers' information systems to general practices, and vice versa
5. the co-ordination of post-discharge care by hospitals alongside, not instead of, general practices, especially in Eastmere and Whinshire.

General practices depended on care networks (see *Chapter 8*) to address these issues.

To summarise, general practices in our study sites had extended services and introduced new working practices for, among other reasons, co-ordinating complex care. However, the greatest constraint – seldom mentioned in research or policy despite being so obvious – was the small scale and narrow scope of general practice services. Patients requiring complex or round-the-clock care were bound to be referred to external providers.

Chapter 7 'Second-responder' providers: organisation-level care co-ordination

Explaining patients' experience of 'second-responder' providers

To care for patients with complex care needs, general practices have to supplement their own services with some combination of CHS, hospital (NHS or private), mental health, social care (local authority or third sector) and diagnostic services (NHS or private). Our study sites were selected to include some in which two or more of these 'second-responders' were organisationally integrated into one NHS trust (publicly owned hierarchy). We next report how the main 'second-responder' providers co-ordinated care provision internally, and how far their co-ordination mechanisms matched, and hence explained, the patterns of patient experience reported in *Chapter 5*.

To recapitulate, our sample of patients reported the following largely similar experiences of second-responder providers:

1. Only 11% of patients thought that they had care co-ordinators outside general practice.
2. Only a minority of patients had care plans.
3. For those who did, individual providers' care plans were more apparent than an overall care plan.
4. About half of the patients reported having care reviews.
5. Some patients reported having insufficient contact time with health workers.
6. Relational continuity with community nurses and therapists was sometimes low.
7. The lack of post-discharge follow-up extended to CHS and care appeared better co-ordinated within than between services.
8. CHS support, especially district nursing, promptly ceased for some patients.

The main between-site difference in patient experiences was the easy transfer between CHS, day hospital and acute hospital in Fivecastles.

Second-responder organisations: care co-ordination commonalities

Care co-ordinator

Only one of our patient interviewees considered that they had a nurse as their care co-ordinator. All of the study site CHS identified case managers for patients with complex, long-term conditions, but there was considerable variation across sites and between services as to which patients had one, the criteria for having one and arrangements for assigning that role. To illustrate the complexity, in Eastmere, patients with two or more unplanned admissions in the past year and taking four or more medications could be assigned a CHS care co-ordinator. In Whinshire, post-acute patients were covered, with each ANP covering (as in Eastmere) a number of designated general practices. In Sedgeton, patients referred to a short-term CHS service (intermediate care, intravenous community therapy, community rapid response) were variously allocated a clinician to assess them and then transfer them to the necessary professionals. Outside the virtual wards, case management in Tarrow was so limited as to make the question of the criteria for having it 'a bit academic' (TP02). These eligibility criteria suggest that patients were sometimes right to

think that they did not have a nurse (or similar) care co-ordinator. One virtual ward scheme uncovered high levels of unmet need, with some complex housebound patients seeing only a district nurse:

[W]e're identifying patients that have never seen anyone. And actually I find it shocking a little bit that I've met really poorly people with end stage lung diseases, diabetes that, I suppose, then the district criteria's they're housebound and that they have a nursing need.

Nurse TP10

Usually the co-ordinator was an ANP or equivalent (e.g. community matron). In Sedgeton, each discipline had a professional responsible for each client, so 'a therapist who is allocated a case will stay with that client right the way through their journey whilst they're with us' (clinical services manager SP07).

In Fivecastles, the care co-ordinators were usually nurses, but there, as elsewhere, a therapist, specialist nurse or other professional might undertake the role:

I'm in charge of that patient, it's my responsibility to make sure that we reach the goals we've set . . . because the intervention is in their home, you're treating that patient as a whole human being, so you're looking at not just physiotherapy needs, you're looking at what that patient needs to keep them safe and independent within their home.

Physiotherapist F08

Health workers' propensity to take on the care co-ordinator role was influenced by the length of the intervention and the degree to which it was task focused. For hospital outreach care, the consultant was the de facto care co-ordinator.

Community mental health services tended to have a single point of access with onward referral to teams or localities and, because of resource constraints, an often pragmatic approach to case allocation. Those assigned a case [usually community psychiatric nurses (CPNs)] tended to act as assessor and care co-ordinator, and to make onward referrals. In Tarrow, the community mental health team usually acted as care co-ordinator, but the older persons' community mental health team meeting would allocate its new referrals one professional, as would the intermediate care team if 'I don't think anything's moving along' (TP04). Two care networks (see *Chapter 8*) also assumed some responsibility.

Care plans

Only a minority of patients believed that they had care plans, and these were plans made by separate providers rather than an overall care plan. Our health worker informants confirmed that each profession or service tended to make its own unidisciplinary treatment plan rather than 'read off' its contribution from an overall holistic care plan. Copies of the unidisciplinary plans for each patient would sometimes be bundled together at the patient's home. Various documents were termed 'care plans', ranging from a checklist agreed with clients (Age UK) to personal care plans, clinical management plans, contingency plans, advanced care plans and district nurses' patient records. For example, Whinshire district nurses made:

1. anticipatory (generic) care plans
2. more specific (e.g. wound management) care plans
3. 'goal-centred' or 'management' plans for complex patients.

The Sedgeton specialist nursing teams' plans set goals, but without strict time limits. Achieving the outstanding goals (if they remained realistic) was what mattered. Such plans typically included patient and GP inputs. In Eastmere, 'personalised' care plans assisted longitudinal continuity of care by indicating, for example, what oxygen level was normal for a patient, which aided timely discharge by showing when the patient's condition had restabilised at its normal level. The Eastmere community mental health team attached considerable weight to 'care' (contingency) plans as they helped in managing mental health episodes. Prompts such as 'have you made yourself a cup of coffee?' or 'have you had a cigarette?' (EP13)

promoted longitudinal continuity by enabling unfamiliar carers (e.g. out of hours) to assume the role of more familiar ones.

As case management was not universal, neither were overall care plans, especially for patients on intensive programmes of care to prevent hospital admission or expedite discharge. On a generous definition, most services had some kind of care plan, the key exceptions being short-term services (e.g. housing, OTs). Despite the collocation of so many services there, Sedgeton patients were unlikely to have one overall care plan. The CHS assembled a set of service-specific plans or goals on paper in a 'yellow folder' at the patient's home, but 'in a crisis it takes a good carer or relative to recognise the need to bring any of the individual care plans into hospital' (geriatrician SP15). Patient involvement in the care planning process was also often limited, particularly if mental health workers were involved, because we are 'talking about very vulnerable individuals by this stage' (team facilitator TP04).

National guidance recommended the Care Programme Approach for planning complex mental health care, but our informants explicitly mentioned it only in Sedgeton and Tarrow. Even among the patients with long-standing complex needs on whom we focused, it was noticeable how few (14%) received any social care, let alone a plan for it extending beyond a 6-week reablement programme.

Care review

About half of the patients in our sample reported having care reviews. Care reviews, where they did exist, were more common for the simpler, condition-specific interventions. Apart from patients in a proactive care scheme, it was the complexity of care that was not reviewed. Review frequency, and which patients had them, again varied across study sites.

Whinshire CHS patients could always request a care review but, we were told, rarely did. For patients who had them, their 'goal centred district nurse care plans' specified timed care reviews. Post-acute care patients were reviewed whenever an ANP visited them, with other patients reviewed when they came to a clinic. In Fivecastles, patient reviews were being formalised into 'visit standards' 'so if the patient's seen daily in a 7-day period, at least one visit is undertaken by a qualified practitioner' (locality manager FP04). Review frequency reflected individual need:

I mean sometimes I'll review somebody monthly, sometimes it's weekly, basically our role is teaching a patient to manage themselves.

Physiotherapist FP08

However, what this physiotherapist described was not necessarily universal. The review process was increasingly being linked to timely discharge (as with Eastmere's community matrons and all district nurse teams) while, at the same time, staff shortages impeded care reviews. Responsibility for review was also being traded, at times, between different parts of the health system (sometimes without financial compensation). District nurses, for example, were often performing medication reviews, diabetic reviews and other long-term reviews for housebound patients. In Fivecastles this was formally commissioned, but in Eastmere it was not funded. Sedgeton CHS staff asked GPs to make the 6-month checks that NICE recommended for patients with heart failure. Our informant was unsure if those checks actually happened.

In contrast, review was normal for reablement patients (commonly on 6-week care packages), who would typically have each visit written up, be monitored weekly and formally reviewed just after the mid-way point to establish whether or not they needed ongoing care.

Review was also integral to mental health care. The Eastmere community mental health service reported that they aimed for 3- or 6-monthly care plan reviews depending on status, but would review weekly during crises, and daily if patients' medication or behaviour warranted it, updating 'their risk assessment/ care plan, every other day, every week, because it needs to be up to date' (CPN EP13). They also reviewed dementia patients 6-monthly rather than yearly (as in NICE guidelines).

Service profile: shortage and specialisation

Patient interviewees reported instances of hurried home visits, often at unpredictable times, insufficient contact time with health workers, often-changing health workers and (for some) prompt cessation of CHS support. All of our study sites reported having insufficient CHS staff, especially specialised nurses, community matrons (or the equivalent) and OTs. Staff shortages reduced the scope for transferring patients even within a provider, and hence reduced flexible and longitudinal continuity of care. 'Blocking' not only of beds but of skilled workers (e.g. district nurses) occurred when a reduced staff complement stopped patients being transferred onwards. Delays in assessment, care and treatment were reported in Eastmere, particularly for physiotherapy. Nevertheless, some clinicians in Eastmere regarded large numbers of patient referrals to them as a sign of success, showing demand for their services. In Tarrow:

I think there's a delay across most services to be honest in that everybody's [community, secondary, social care] under the same pressures.

Nurse TP05

There, CHS were mostly limited to working hours of 5 days per week and lacked sufficiently qualified community matrons for the virtual wards:

I am the only person at the moment, for the matrons, who's got health assessment and who can prescribe.

Nurse TP10

The CHS heart failure service at Sedgeton was two-thirds under strength, relying heavily on the health-care assistants as 'sort of care co-ordinators'. Such shortages directly affected longitudinal continuity of care because 'there's a memory for the person who deals with that particular area of care that obviously improves outcomes for the patient' (speech therapist SP01).

Occupational therapists and carers were in short supply in Fivecastles CHS. Whinshire CHS staff said that they had good specialist services (e.g. speech and language), but other services were stripped of staff (rehabilitation services had only 2 hours of podiatry input per week; OTs were scarce). There were insufficient services (e.g. night sitting) for patients entering residential care. Staff shortages leading to expedients such as ad-hoc staff redeployment may explain why patients reported discontinuity of the staff who made home visits, as may high numbers of part-time staff.

Staff shortages were more severe in mental health and social care. In Eastmere, this bottleneck stopped CHS transferring patients onwards. Redundancies and downgrading had made it difficult for the Whinshire mental health team for older adults even to deal with patient crises. Mental health services there faced a shortage of rehabilitation beds, there were no psychotherapy services in the county, and the well-being service was of high quality but had too little capacity, which became a problem when making a care plan for someone with acute psychological problems or anxieties. In Sedgeton, the shortages had a partly financial cause, but it was also difficult in any case to recruit specialised staff, and indeed community nurses generally, with the right experience. The CHS often backfilled vacancies, but that only depleted another team. In Fivecastles there were also reported shortages of welfare benefits advisers and befrienders (volunteers).

Workload pressures had two opposite effects on the specialisation of primary care labour. On the one hand, new specialisations appeared, such as primary care dementia practitioners (Eastmere). To work more flexibly (e.g. in acute care at home schemes) staff required higher skills and hence they cost more to employ, which had to be weighed against any savings resulting from higher productivity:

Up skill for flexibility – especially for rural areas, with some of the roles that we have, I'd like to tweak so that people could do more, especially our support workers, they can't take blood and things like that.

Nurse TP10

Against this, financial pressures made CHS managers reluctant to set 'precedents' for additional or different services, and encouraged task delegation (e.g. in Eastmere, delegating 6-monthly reviews of dementia patients' care to a health-care assistant). Such delegation could have unforeseen advantages in that more regular contact generated trust and helped reveal patients' needs 'once you get to speak to a carer there's often other things going on' (CPN EP14). Similarly in Whinshire CHS, the caseload was stratified from low- to high-complexity patients, with district nurse work increasingly concentrated on complex patients. In some district nurse teams, the health-care assistants scheduled the nurses' caseloads. Sedgeton CHS employed 'roving GPs' who cared above all for (mostly elderly) patients recently discharged from hospital, where exacerbations would otherwise have resulted in readmission.

Co-ordination mechanisms

Line managers tended to allocate district nurses' work in task-oriented ways that maximised output ('efficiency') rather than cross-sectional continuity. Partly they resorted to ad-hoc rostering in response to staffing pressures, but to varying extents at all study sites CHS had been centralised on a locality basis. Economies of scale were one motive, and the desire for 'seamless' CHS (enabling, say, district nurses to work more closely with community matrons) was another.

Even under single management, working practices were often limited to a single occupational 'silo', not standardised or co-ordinated organisation wide. Each CHS team in Sedgeton had different ways of selecting a patient's key worker (after assessment or triage; whoever was available; by locality). All of this variation occurred within one manager's span of control. Information management was often equally disparate. In Eastmere 'we have cardiac, we have respiratory, all using different paperwork, diabetes, different paperwork, Parkinson's' (team facilitator EP07). Paper-based care plans in the home then became the only way of communicating between staff. The need to care for patients around the clock also increased discontinuity of care (e.g. in Fivecastles patients went to dressings clinics at the weekend instead of a district nurse visiting them).

In all study sites, providers used 'horizontal' MDTs to manage complex care. Nevertheless, the 'silo' mentality reported among professionals at all sites was an obstacle, commonly taking the forms of not trusting other professionals' assessments and of non-communication. The acute care at home scheme in Eastmere lost early recruits because 'they were A&E [accident and emergency] nurses and had it tattooed on them' (team facilitator EP07). Another area had a history of non-cooperation between equipment and learning disability OTs. In Sedgeton:

The word 'team' has begun to mean people sitting in the same office, rather than virtual multidisciplinary teams which I think are actually the foundation of what most people do. Because you can't all sit in one office [laughs] all of the time.

Speech therapist SP01

Then the word 'team' was little more than a euphemism for a hierarchical, uniprofessional department whose members tended not to see themselves as part of a larger care pathway. Consequently, one 'team' (e.g. heart failure) might have no direct access to services provided by another (e.g. physiotherapy, occupational therapy):

So unless a patient has COPD then the OT in the respiratory team is bound not to take those patients on and equally if the patient doesn't have cancer, the therapists within the palliative care team can't take them on.

Nurse SP04

Physiotherapists could refer to podiatrists but not vice versa, yet other 'teams' in the trust could readily transfer patients to one another.

Vertical integration

Second-responder providers substituted primary for hospital care through a combination of:

1. diverting potential admissions from the ED 'front door'
2. expediting hospital discharge at the margin
3. hosting and/or staffing care network co-ordinating bodies (see *Chapter 8*).

Mental health services were vertically integrated, with consultants working in both community and inpatient mental health services. When a CPN thought that a patient needed consultant attention, the referral still had to be routed back via the GP, conforming to the consultation model of care co-ordination. However, once referred to a consultant, patients could readily be transferred between services within the trust, for instance when hospital-based services were transferred to community clinics, even to support groups.

Wider organisational integration

Where attempts were made to integrate organisations, it took some years for interdisciplinary and interservice teams to develop and accumulate good working relationships, trust and mutual knowledge.

Community health services with acute services

Our patient interviewees in Fivecastles described their transfers between CHS, acute hospital and the various day hospital services. The same geriatricians worked across the wards and day hospital. Patients could immediately 'step up' or 'step down' between community, intermediate and acute care without external referral. The day hospital gave 'a sort of one-stop shop' for GP referrals (70% of its caseload) and patients liked it. They could access a range of equipment in a safe environment, promoting confidence and socialisation, and follow a flexible treatment programme throughout the day rather than treatment at allotted times.

However, conventional line management did not reach very far into the day hospital. Its geriatricians were based in the two DGHs and:

[N]o one sort of takes charge of the day hospital [. . .] It's very much team working and I think that's one reason why it works, because there isn't a manager to oversee everything, so everyone pulls their weight and works [. . .] We meet every morning to discuss patients and will set up a meeting if there are problems but [it's] difficult to schedule team meetings with part-time working, rotas, patients in, etc.

Therapist FP14

Perhaps unwittingly, this regime resembled the Netherlands' *Buurtzorg* system²⁵⁷ of giving community health workers high levels of autonomy and responsibility. Transfer-of-care co-ordinators worked in the ED assessment unit to divert patients and avoid admissions:

Somebody else had fallen, OK we'll see to her laceration, we'll now send her to an occupational therapist to see where do they need their grab rail, do they need their couch raising, you know things like this, put them in the Falls Prevention Programme.

Locality manager FP04

Even within the trust, lack of communication could sometimes inhibit continuity of care. CHS were not always informed when their patients returned to hospital, and the care of those patients who missed outpatient department appointments (even when this occurred as a result of sickness with which CHS were already involved) was referred back to the GP.

Because it was the same organisation, community and day hospital patients were able to return to the DGH for limited periods without needing another GP referral. As noted, CHS transfer-of-care co-ordinators provided an ED 'front-door' referral diversion service. Specialist nurses had become hospital based but 'they're still very accessible to us' (locality manager F04) and would visit patients with the community nurses when required. The local hospice-at-home was officially an external provider, but:

We sort of classify them with us [combined acute and CHS trust] because I think there is some reciprocal funding and [. . .] they're partly charity funded as well.

Locality manager F04

By contrast, the main community hospital for our Eastmere study general practices was not just managed by a separate trust from the CHS, but by a trust located in, and mainly serving, another CCG.

Community health services with mental health services

Community health and mental health services in Whinshire were organisationally integrated as one trust. This trust was rolling out a primary mental health model under which mental health services were seen as a normal part of primary care. Consequently, mental and other community health care was integrated through interdisciplinary teams. The community elderly care team included geriatricians, psycho-geriatricians, CPNs, OTs and nurses. The district nurse team lead's role was also to better integrate physical with mental health care, especially for patients who were in and out of hospital with long-term conditions. In the absence of common information systems, this included working with a mental health counterpart to identify patients who were on both caseloads or could benefit from joint input. However, an additional referral from the GP was still required before the patient could access additional services within the same trust that the GP had already referred the patient to for other reasons. Representatives of the older adults' mental health team were meant to attend weekly meetings at the mental health hospital, although pressure of work curtailed this to discharge planning meetings only. Until recently, social care staff were seconded into CHS teams, but financial austerities had scuppered this arrangement.

Nevertheless, the parallel, occupationally based 'silos' for CHS, mental health services and therapies provided by social services were resilient. The well-being team and psychological therapy teams 'just work very differently [from us in CHS], even though we're all in the same organisation' (nurse WP03). The older adult mental health team still did not have non-mental health nurse members and had lost its social worker members, which made it harder to maintain longitudinal continuity between health and social care. Mental health services were vertically integrated. Day hospital mental health services had largely been closed in favour of cross-sectional groups, whose expansion was limited mainly by the trust's resources.

Whinshire was unusual in having quite integrated medical records for frail elderly patients, with read-write access for other health and social care staff besides GPs. Nevertheless, data input remained laborious. One informant claimed that it could take up to half of the working day:

[I]f you've done it and haven't recorded, you know, you haven't done it, whether it's in the patient's own notes it has to be on [proprietary system name] (the spiros and the phone calls).

Nurse WP03

Mental health services still had a separate information system whose records were not directly accessible to other trust staff, but the trust was considering a combined data warehouse.

Community health services with acute care and social services

When social workers at another site (Tarrow) began working as part of the mental health trust team, the benefits of organisationally integrating health and social care were immediate: '[D]elayed transfers of care were eradicated within 6 weeks', moving the trust from being 'about the worst in the Strategic Health Authority to the best' and this where there was 'a high performing acute sector and [. . .] an underinvested in community sector' (manager TP01). Expenditure had to be shifted so that there were no overall savings,

'So in a place like [county], high performing and quite small, the benefits are clinical and quality, clinical quality, not economic' (manager TP01). The subsequent experience of organisational disintegration revealed, with hindsight, how much easier organisational integration had made co-ordinating and maintaining longitudinal continuity of care:

[W]e learnt so much about each other, adult social care and health, because we were together for several years [. . .] We weren't given the 5 years to really make it embed into practice [. . .] it's such a great shame.

Nurse manager TP06

Towards the end of the study period, the integrated organisation in Tarrow was partly dismembered. Social services reverted to independence, but acute and CHS services remained organisationally integrated in one NHS trust. Our account of the organisational integration of health and social care, therefore, reports the integrated period, illuminated by contrasts with the subsequent separation.

This trust ran a pilot 'virtual ward', organised within the trust. (See *Chapter 8*, which describes a second, separate 'virtual ward' that GPs ran.) It was consultant run and staffed mainly by nurses and community matrons, 'assertive, highly skilled nurses who are well versed at risk assessment' (nurse manager TP06), who worked largely in the acute hospital; they identified, in the ED, the clinical assessment unit and ward rounds, patients who could be cared for at home. On discharge:

[T]he medical responsibility lies with the consultants in the hospital, not the GPs, so that's been a real change for the consultants and these matrons have spent a great deal of time building the confidence of the consultants.

Nurse manager TP06

Patients, therefore, did not necessarily have to be medically stable to return home. A community sister took responsibility for the patient's ongoing care (including a 24/7 response capacity). Both virtual wards had integrated electronic patient records with read-write access for all the relevant health professionals in the trust, increasing informational continuity.

The virtual ward scheme described above initially focused on expediting discharges and so reducing hospital average length of stay, rather than entirely substituting primary for inpatient care. The team of consultants, community matrons (who could prescribe), NPs and other nursing and support workers provided care in discharged patients' homes. However, the virtual ward now also receives direct referrals from the ED, the clinical assessment unit and outpatient clinics, including podiatry and orthopaedics.

In this site the integration of CHS, social care and acute hospital care had little impact on primary care services themselves, but, as reported above, it did make it easier to access some of them.

Patient experiences and care co-ordination within second-responder providers

Besides the foregoing matches between second-responders' care co-ordination mechanisms, or lack of them, and the patient experiences reported in *Chapter 5*, we found the following mismatches.

Behind-the-scenes co-ordination mechanisms invisible to patients were, above all, case management and the corresponding MDTs, care plans, care reviews and information systems. Patients' accounts also suggested that the person they perceived as the locus of care co-ordination was the person with whom they had the most contact and not necessarily their formally designated care co-ordinator. The extent of NHS trust integration was not invisible to patients, but it was unlikely to interest them much, either. As noted, few of our patient interviewees had used mental health services, although this comorbidity was common.

Again, patients' resources (and hence access to privately purchased care) and inclination to manage their own care are non-organisational explanations of (parts of) their experiences of care co-ordination. Consultant resistance might superficially be regarded in the same light.

Higher-level constraints on care co-ordination

Other influences on patients' experience of continuities of care – also invisible to the patient – were non-organisational in the sense that a single organisation was unlikely to influence them. They reflected higher-level health-system governance, such were the interprofessional demarcations and rivalries, staff shortages and the reorganisation of services under financial pressure. More immediate interorganisational constraints on care co-ordination at second-responder level were:

1. which services were not internally available: inpatient, mental health or social care services depending on the case, and always primary medical care
2. the presence and scope (or absence) of multiagency care teams
3. closure or non-interoperability of other providers' information systems
4. delayed transfers owing to capacity bottlenecks in the next provider(s) along the care pathway.

This and the previous chapter show how care co-ordination within provider organisations was constrained by the limited range of services that each could offer (particularly the absence of primary medical care in NHS trusts and the small-scale general practice services). Across the study sites, provider organisations depended on the following external resources for their patients' complex care:

1. services not available in-house
2. multiagency teams to provide patients with access to those services
3. external providers willing to colocate additional services at the general practice or trust
4. other providers' information systems being open to general practices and vice versa
5. removal of capacity bottlenecks that delayed patients' transfer to the next provider(s) along the care pathway
6. post-discharge follow-up by GP and/or CHS
7. finance for additional care co-ordination work.

Patients had a greater proportion of ongoing contacts with hospitals in Fivecastles and Whinshire but lower levels of engagement with CHS. Fivecastles also had higher than average levels of engagement with private providers. Hospital-to-hospital communication was problematic in Whinshire, the only site to have two DGHs serving its patients.

Often, one provider (e.g. CHS) also hosted a care network co-ordinating body (e.g. a referral hub). The same person or group who co-ordinated care within that organisation might also co-ordinate between providers. We next report how the care networks achieved that.

Chapter 8 Transitions between providers: continuity, care co-ordination and care networks

When an integrated organisation cannot provide all the services needed for complex care and has to refer the patient elsewhere, care networks – whether emergent or managed – come into play as care co-ordination mechanisms. This chapter reports how the care networks in our study sites addressed the issues identified in *Chapter 7*. We present the varieties of care network (which coexisted in each of our study networks) in ascending order of organisational formality, scale and depth of co-ordination.

The consultation model

The archetypal consultation model of care co-ordination (see *Chapter 2*) places the primary care doctor at the hub of referrals to, and back from, other provider organisations. The primary care doctor tells (or, more politely, requests) the other provider to treat the patient as the doctor specifies. To illustrate, a GP in Sedgeton:

had one incident with a patient who wanted [. . .] to die at home, who'd expressed that but whose carers kept on calling 999 ambulances because they weren't able to cope with her situation at home. And so, in this meeting, I spoke to the head District Nurse who put a 24-hour sitter in the property for 3 days and there was no ambulance called, the end-of-life care was seamless and she died peacefully in her home, which was what she wanted.

GP SP10

Here, the ability to co-ordinate care effectively was explicitly facilitated by a meeting of the IPCT. More generally, however, this delegation-like approach may explain why third-sector informants in Sedgeton and Whinshire told us – although patients (and, less surprisingly, GPs) never did – that GPs were not always good case managers. For non-clinical problems, voluntary bodies in Sedgeton felt that they had to convince GPs that when referring a patient ‘they did not need to tell us what to do – just tell us there’s an issue’ (voluntary organisation organiser SP08).

Certain interorganisational referrals still had to be made via the GP. Hospital discharges were referred back to GPs even when the patient mainly needed different care (e.g. district nursing). GP budget-holding reinforced the consultation model. Patients had at times to be referred back to the GP not for any clinical reason but for budgetary authorisations, even quite trivial ones (e.g. for a walking stick in Sedgeton). Although transfers within an integrated provider did not usually require referral back to GPs, there were exceptions (e.g. referral from ANPs to their mental health counterparts went via the GP even when the ANP and the CPN were in the same organisation). The amalgamation of organisations reduced the proportion of interorganisational patient transfers that had to be made via the GP, whereas organisational separation or the transfer of staff (e.g. physiotherapists in Whinshire) to another organisation increased them.

Emergent informal care networks

Through habitual referral, informed by local knowledge, personal contacts and trust, informal de facto care networks had long since developed from the consultation model. The Fivecastles and Sedgeton GPs we interviewed said that they preferred to refer patients to ANPs whom they already knew. An ANP corroborated this:

I think a lot of it depends on each individual ANP, do they know what's out there, not everybody necessarily does.

Nurse TP03

A Fivecastles GP contrasted their arm's-length relationship with district nurses with their relationship with the palliative care nurses:

You know, I have their mobile numbers, I know their faces, they come to our palliative care meetings once a month, you know, it's a completely different ball game. It's just proper joined-up care and that's how it should be.

GP FP03

It took time to build up mutual trust and working relationships, which, moreover, did not always develop evenly.

Interorganisational information exchange

Referrals require information exchange between organisations. The exchange of health records between providers under different ownership was, in every study site, incomplete, even lacking, owing to:

1. Information governance rules preventing data exchange (e.g. for risk stratification) and sharing care plans, especially (but not only) between social services and CHS. In Eastmere we were told that the lack of a common care plan was because of legal requirements connected with individualised care budgets.
2. Variegated information systems, some ill designed for information sharing, even if that was wanted. Thus, nursing records and care plans might be held electronically (e.g. in Eastmere), but even when access had been negotiated data still had to be scanned or retyped into general practice systems. Because hospital, social service, mental health and third-sector systems rarely communicated:

We don't have one record for one patient. One patient could have five different services calling in. All those records are archived somewhere different and I may not know what the cardiac nurse has said, you know. I may not know what the consultant has said, in [hospital], I may not know lots of things.

Nurse EP08

3. Non-automated systems requiring dual data entry. For example, Eastmere and Whinshire CHS staff made notes on paper at the client's home and then re-entered them onto computers back at the office. (Sedgeton staff had no electronic systems and were, therefore, spared this task.) CHS staff often had to go to the general practice to read patients' records there. There were separate (partly duplicated) financial, clinical and management systems.
4. Unreliable connectivity, especially in rural areas:

Some days it will work; other days it won't.

Manager EP18

5. Clinical coding inconsistencies: different general practices coded similar activities differently. Hospital coding of mental health problems was erratic.

Colocation

To varying extents, all the study sites had replaced colocation at general practices with basing CHS staff at centralised locality offices. In Eastmere, Fivecastles and Tarrow, CHS teams that included district nurses, OTs, therapists, assistant practitioners and support workers were each linked to clusters of general practices. In contrast, organisations were colocating individual staff members. In Eastmere, for example, primary care dementia practitioners employed by the hospital trust were colocated in GPs' surgeries, providing outreach to community hospitals and nursing homes. Elsewhere, CHS, mental health services and voluntary organisations were providing in-reach counselling, podiatry or care navigation services to GP

surgeries, social service offices and district nursing teams. In one instance, a voluntary organisation provided a follow-up check for patients who had been discharged from hospital because:

people were coming to our attention 6 weeks after they were discharged from hospital with actually quite a lot of need that hadn't been referred through to the hospital based services.

Manager WP08

Given time for trust and good working relationships to form, the benefits of colocation were described to us as being quick, easy access to recent information about patients; easy access to advice; joint problem-solving; shared, consistent decisions about patients; mitigating the problem of inaccessible patient records; and easier informal ('permissive') referrals. For co-located CHS and social care staff (Eastmere) 'you can walk up and down, you can discuss easier face to face' (manager EP06). The Fivecastles general practice noticed the value of colocation once it ceased:

[T]he district nurse would come in 11.30, 12.00 each morning when we finished our surgery so that we could liaise, you know, face to face a proper relationship [. . . Now] you have to fax some central place [. . .] So you send off this form into what feels like the ether and you haven't got a clue really whether somebody's going to get back.

GP FP03

The experience was similar in relation to collocating the memory service and intermediate care team:

[I]t makes for easy referrals doesn't it? And you're on hand and you can deal with things quite quickly.

Team facilitator TP04

Pharmacists were in some areas also colocated with general practices and undertook patient reviews.

Colocation could short-circuit the effects of separate record systems and circuitous ('consultation-model') referral routes, but it could not remove the underlying organisational blockages. Neither was colocation sufficient to stimulate communication between staff, even within the same organisation, if they were simply personally uncommunicative. At Sedgeton, some hospital outpatients, CHS and mental health services were colocated in a large, purpose-built building, which (some informants told us) made it easier for them to obtain information and advice and talk informally across disciplines rather than referring patients into 'the ether'. However, others told us that all of this colocation did not seem to have made CHS teams especially communicative with each other, nor were they when different services operated out of, for instance, the same community clinics. Colocated staff would not necessarily communicate with each other unless they saw a practical reason. Although described as a 'polyclinic', the building was more a venue for large-scale hospital outreach than a polyclinic in the classic sense. It was treatment and clinic focused rather than focused on cross-sectional continuity of care.

Managing care co-ordination through care networks

In all five study sites, formally managed care networks had been established, the better to co-ordinate care across organisational boundaries. Earlier informal interorganisational teams that had already developed 'from below' (Eastmere, Sedgeton) were incorporated into the newer care networks. These care networks typically aimed at admission avoidance, facilitated discharge and improved horizontal co-ordination by developing new models of long-term condition management to help patients to remain independent for longer and have more choice in their end-of-life care. They combined, and did not sharply distinguish between, horizontal and vertical co-ordination.

Interorganisational care process

Accordingly, the care networks assembled care pathways for care groups, or even individual patients, across separate providers. These pathways were often time limited (e.g. to 6 weeks for most post-discharge patients). Networks established a single entry point for referrals, with swift, formalised assessment and triage for most patients and then referral to a 'second-responder' provider. Two networks (Sedgeton, Whinshire) used 'front-door' teams at hospitals to 'pull out' incoming patients whose admission could be avoided. (The CHS rather than an interorganisational care network did this in Fivecastles.)

Only certain patients had cross-organisational care plans (see *Chapter 5*), but it was usually those whose care was co-ordinated by a network. Whinshire, for example, had developed an integrated EHR to which some services, including hospital wards, had read-write access, although not all did. High-risk patients had personalised care plans that included advice about what to do should they suffer an exacerbation. In Tarrow, the virtual ward teams used such plans to review patients' condition daily. A MDT reviewed 'key' patients in Whinshire to decide when the next review was due and who would update the patient's care plan. One locality team also shared its social care plans with voluntary services. In Fivecastles, some general practices (although not our corporate example) had an electronic care record for patients approaching the end of their life and shared it with all urgent care providers. However, for most patients and health and social care providers this did not apply, causing 'quite a lot of duplication, potentially going in for support of service users and not very, potentially, not very well co-ordinated in places as well' (manager FP09).

Network co-ordinating body

Care network co-ordinating bodies went under various names: 'referral hub', 'assessment service', 'emergency intervention service' 'proactive care', 'virtual ward'. In our study sites, either CHS hosted the co-ordinating body or the providers with the largest or most problematic interfaces jointly did so (Eastmere and Whinshire). In some sites the network co-ordinating body had its own budget or (in Eastmere) its member organisations supported it only in kind. Elsewhere there were pooled budgets for jointly managed services.

Care co-ordinators

Care networks had also assumed care co-ordination responsibilities to various degrees, sometimes co-ordinating their patients' care themselves, but sometimes assigning it to an existing service. The networks usually co-ordinated care through a combination of case manager and interorganisational MDT.

Case management by non-doctors was available at all sites, typically for a limited time, to avoid hospital admission or expedite discharge. Within the limits of the information available, case management was often based, at least in part, on formalised risk assessment (but not always: GPs frequently felt that the available tools did not identify any patients of whom they were not already aware, and relied on their own clinical knowledge). Sites varied in terms of which patients were eligible for case management, although in no sites were all patients eligible. In Eastmere, the 'grey area' of patients who seemed still to lack a care co-ordinator caused staff a lot of stress. However, some patients had no designated care co-ordinator because (we were told) their needs might be too complex, high level and unstable; responsibility for care had to remain flexible.

Care co-ordination by case management was, in our study sites, a hybrid arrangement, transitional between the consultation model and care co-ordination by teams. It was consistent with the consultation model principle in that the GP might delegate tasks – here, care co-ordination – to others, and in that the new case manager replaced the GP at the hub of a 'star-pattern' configuration of referral links. However, in doing so, it also partly transferred the *captant* role. (In some places, although not our study sites, nurses have entirely replaced doctors in that role.) New or exacerbated health problems might still be referred back to the GP, but more selectively now:

[B]efore, they [patients] would have gone back to their GP for any health queries, the absolute expectation now is [...] they must first, in the initial instance, come to ICT [intermediate care team]. Because obviously we wouldn't want to be escalating it to a GP when it should be dealt with in-house, and the majority of those would have never have needed GP view at all.

Manager WP16

This arrangement seemed most developed in Eastmere, and least so in the more silo-like Sedgeton CHS.

The care co-ordinator role might shift between case manager and multiagency team:

I would say yes, we're the case managers, but if you feel like there's an exacerbation, need more intensive support then that care will transfer to ICT [intermediate care team] and then, so there's not a duplicate, and then they would maybe refer that patient back to me.

Nurse WP03

A patient in Sedgeton might first be assessed by, say, a neurology team, and then transferred to another team to assemble an overall package of care. Except for urgent referrals, which were allocated on a duty rota system, referrals to the Tarrow older persons' community mental health team were triaged at a weekly team meeting, which included a consultant, and were allocated depending on area and type of need. The person who first assessed the patient would, if appropriate, become their care co-ordinator.

Although patients might have a named care co-ordinator, much of the actual co-ordination work was undertaken by interorganisational, multidisciplinary primary care teams. Referrals between CHS and social care were often decided by case conferences and reviews. The nomenclature ('multiagency group', etc.), membership, scale and scope of these teams varied. Some were organised by locality; others were CCG wide or on some other scale, or with different teams concurrently serving populations of different sizes (e.g. when small specialised teams could not be divided among localities). Often several teams were available with different specialist skills (e.g. mental health, stroke, frail elderly). Typically – but not always – teams met at general practices with at least one GP attending, although in one of our Tarrow study practices such meetings were (unusually) attended by virtual ward staff and several of the practice GPs:

[Y]ou'll get whoever's available on the day, so you may end up with three, you may end up with six, eight.

Nurse TP10

However, there were still communication gaps between the (other) district nurses and the community ward team, and so weekly meetings between the district nurse and the virtual ward's community matron were also instituted:

[H]opefully it's only about half an hour. And we go through anyone who's new to the virtual ward, and anyone who's been discharged and needs follow-up from district nursing.

Nurse TP10

Indeed, multiagency care networks undertook most of the MDT activities that occurred at the study general practices. Our study general practice in Fivecastles also continued to hold monthly 'Gold Standard Meetings' with palliative care nurses and district nurse case managers for case reviews (in Sedgeton these became part of the IPCT meetings).

Network resources

The resources available to each care network depended on the service configurations within the member-organisations (see *Chapter 8*), which organisations participated and how actively. Care networks in this study variously included general practices, CHS, mental health, acute trusts and social services. Some used community hospital beds for step-up/-down care, with consultant or GP medical input. Hospital doctors participated in some of the Sedgeton and Whinshire teams. They also varied in scale. For example, the ambulance service and a practice-based commissioning consortium covering about 90% of the county's population participated in Whinshire, whereas the Tarrow virtual ward served only part of the county. Care networks often reached into the ED 'front door', sometimes into the hospital wards or meetings with consultants.

Eastmere GPs referred patients to the care network, but thereafter made little further input to it (similar to GP behaviour after referral to a specialist¹⁸¹). GPs were, at times, conservative about referring to new services, fearing that they would lose control over quality of care (Fivecastles and Eastmere). We were frequently told that some GPs and nurses found care networks easier to accept than others.

Social services participated actively in care networks in Eastmere, Whinshire and Fivecastles, but more tenuously in Tarrow (despite previous collaboration) and Sedgeton. Social care providers also participated as, for example, in Whinshire, where an arm's-length trading company had assumed the county council's reablement and care functions. Social services in Fivecastles had a programme co-ordinating services for providing social support for, for instance, bereaved or socially isolated people. Funded by the NHS, voluntary-sector organisations managed practice-based community workers in collaboration with a central intelligence hub. Whinshire had a range of preventative programmes driven by the voluntary sector, but across the study sites voluntary-sector involvement was often reported as being underdeveloped or undervalued, and initiative specific.

Mental health services participated in Tarrow, fragmentarily in Eastmere and Fivecastles, and not yet in Sedgeton. (A single trust provided both mental health services and CHS in Whinshire.) The well-being service in Sedgeton was a collaboration that included a GP-led social enterprise. Several informants involved in other teams in Sedgeton (and Fivecastles) noted, however, the neglect of mental health in their meetings, despite the significance of psychiatric problems in 'frequent flyers'. All of the networks were also attempting to involve third-sector providers more in service delivery, although sometimes from a low base. Patient participation was 'planned' in Whinshire but not reported elsewhere.

The care networks obtained varying degrees of compliance with their preferred working practices. To varying extents, unclear and inconsistent appropriateness criteria, and different administrative procedures for referrals, were described in all our study networks. In Eastmere, some staff had the problem of 'not knowing properly where we can, what we can access, when we can access it and how we do that' (manager EP20).

Seeing the care network's referral rules as a cause of delay, staff would work around them. Staff in the new acute care at home service, for example, encouraged direct referrals to themselves so that they could conduct a full assessment and refer on as necessary, rather than do so via the referral hub. Member organisations' roles were sometimes confusing. For example, both CHS and the county council in Fivecastles ran something called a 'falls service'. None of our informants was sure what the difference was or when to refer to each. Without clear referral or triage criteria, parts of CHS could (and, in Eastmere, did) become catch-all destinations for all patients except those who obviously needed specialised (e.g. mental health) care, thereby acquiring a large caseload.

Informal care networks continued to develop alongside the new official ones. The manager of the acute care at home team in Eastmere said of his staff, 'everybody refers, should refer to everybody else in the community and that's what makes the community' (manager EP06).

Local knowledge facilitated what our informants called 'permissive referrals'. The carers' service in Eastmere, for example, informally referred carers to adult social care, to the community mental health team and to voluntary agencies because they had established good personal relations with those providers. Against this, voluntary-sector workers in Tarrow encountered both health and social worker resistance to their participation at first, although relationships gradually improved.

As noted, the study networks differed in which services were integrated into a single organisation and hence in which interorganisational boundaries remained:

- Eastmere, Sedgeton and Whinshire had an interorganisational boundary between CHS and acute services. Fivecastles and Tarrow did not.
- Fivecastles, Eastmere, Sedgeton and Tarrow had an interorganisational boundary between CHS and mental health services. Whinshire did not.
- Fivecastles, Eastmere, Sedgeton and Whinshire had an interorganisational boundary between CHS and social care. In Tarrow, this boundary, which had been absent for several years, was reinstated during the study period.

However, these different configurations of interorganisational boundaries made little difference to what care co-ordination mechanisms existed and how they were used across the remaining interfaces.

Remaining interfaces

The main practical purpose, and to varying extents effect, of the care networks was to minimise interorganisational barriers to continuity of access. However, in all of the study sites the following barriers remained:

1. *Information flows* were incomplete and often laborious to maintain, partly for technical reasons, although Whinshire demonstrated that these technical problems are largely soluble. This site was beginning to address the interface between physical and mental health and social care (in all study sites a problematic interface) as a prelude to better risk stratification. The barriers were of governance and organisation, resources and professional cultures.
2. *Care pathways and the consultation model* were mismatched, especially regarding discharge from hospital, in the interorganisational flows of information, referral and budgetary authorisations that each required. Patients were formally discharged to the GP, whereas what the patient often needed immediately was CHS support. The construction of additional interorganisational care co-ordination bodies alongside the GPs' co-ordinating role can be understood as a workaround for this problem. The consultation model created apparently unnecessary administrative 'round trips' from another provider to the GP and back for referrals and budgetary authorisations (cf. the vividly trivial example of the walking stick).
3. *Paywall barriers* created bottlenecks and were irrelevant to quality of care:

[W]e looked at 100 people who'd been referred into adult social care but were waiting for an assessment. Twenty-four per cent of people had passed away before they got their personal budget and 17% of people had to go into residential care.

Voluntary organisation organiser TP08

[T]hey have had that 30-page document to fill in, you know, and it's tick, tick, tick, tick, tick. And they find it hard, very hard, to keep up with what's going on locally, so they do not have that 'good life' discussion; they do not have that person-centred discussion.

Voluntary organisation organiser TP08

In elderly mental health care, the speed with which a patient's condition could change meant that sometimes health workers had to start the whole transfer again, 'so it's not good' (TP07).

1. Capacity mismatches existed between successive providers in the care process, each bottleneck prolonging the preceding stage of care. In general, the policy of caring for people at home was thought to be under-resourced. Such bottlenecks were reported in social care, physiotherapy and mental health services at all sites, and in certain other services at each site: for example, in occupational therapy (Whinshire and Tarrow); befriending services (Sedgeton and Whinshire); 'low-level' psychotherapy (Whinshire and Sedgeton); day care (Eastmere, Tarrow and Fivecastles, with funding being withdrawn in Whinshire); NHS-funded nursing home beds (Sedgeton, Eastmere and Tarrow); care agencies (Eastmere and Tarrow); local rehabilitation services (e.g. cardiac rehabilitation programmes in Eastmere and Sedgeton, and diagnostics and community hospital step-up capacity in Eastmere); and between EDs and hospital wards. The bottlenecks prolonged the care process, disrupted its continuity and could be wasteful: 'if somebody has to travel to [hospital] every day just to have their INR [international normalised ratio] and their clexane done because they have had a PE [pulmonary embolism] or a DVT [deep-vein thrombosis], I could do that at home' (clinical facilitator EP07).
2. Weak or missing interorganisational links, for instance between the CHS and parts of the mental health trusts (Fivecastles and Sedgeton), and mental health trust non-participation in the Eastmere network. Small organisations (including some general practices) or departments within organisations (e.g. specialist nursing teams with just one or two staff) could ill afford the staff time required for care network meetings.
3. Mismatched financial incentives and managerial targets between provider organisations adjacent on the care pathway: for instance, QOF versus tariff (payment by results) payments rather than whole-pathway payments, and targets formulated in terms of speed of throughput rather than continuity of care.
4. Organisational separation often meant separate location of services and their staff. Colocation projects were a workaround.
5. New organisational boundaries exacerbated the above problems. In Tarrow, the reversion to separate health and social care providers meant that 'there are single points of referrals [in an integrated organisation], now we have got two, you know, it's just got more complicated and I struggle to see how it's become more cost-effective' (nurse manager TP06).
6. In mental health services, 'what would enhance it [longitudinal continuity of care] is a rapid funding panel process because sometimes we perhaps have done our bit and we are left holding on to someone unnecessarily because of the protracted funding' (team facilitator TP04).

These barriers to care co-ordination were unevenly distributed across the interorganisational boundaries in the care networks that we studied:

1. Between general practices and NHS trusts, all of the above barriers were observed.
2. Between NHS providers (both general practices and trusts) and social services, barriers 2, 3 and 4, and in some study sites 6, were present.
3. Between acute and CHS trusts we found barriers 1, 2 and 0.
4. Between CHS and mental health services we found barriers 1, 2 and 3, and in Eastmere and Sedgeton barrier 6.

The managing bodies in every network developed increasingly formalised and comprehensive solutions to these problems, but they were symptomatic responses rather than ones that addressed the underlying structural causes.

Care networks' dependences on health-system governance

Certain NHS-wide governance structures and higher-level NHS management both enabled and constrained the networks' care co-ordination work. The relevant higher-level governance structures were:

- the consultation model, which is heavily institutionalised within the NHS
- information governance regulations and law
- paywall barriers to accessing services
- the fact that after the 6-week time limit patients had to be financially assessed before receiving ongoing social care
- institutionalised 'cultural' differences between professions.

The care networks, therefore, depended on higher NHS management bodies, above all CCGs, to help them address the following issues:

- establishing care networks and obtaining providers' participation therein
- adoption of interorganisational care processes, thereby reducing the number and increasing the match of interorganisational interfaces
- closed, non-interoperable provider information systems with inconsistent clinical coding and lacking risk assessment data
- adoption of interorganisational care plans and health passports
- pooled budgets
- capacity imbalances between providers
- service location
- mechanisms for capturing evidence of patient experience for use in designing care co-ordination.

Chapter 9 Care co-ordination and health-system governance

Clinical Commissioning Groups and H&WBBs were responsible for the horizontal and vertical co-ordination of services provided by their member practices and other commissioned providers, and for the overall governance of their local health economy. We next report how these bodies aided (or impeded) care networks' attempts to transcend the organisational barriers to care co-ordination, and hence to continuity of care.

Managerial discretion at care network level

Creating care networks: obtaining provider participation

In all study sites, the PCT, or later CCG, had either established new care networks (Fivecastles and Tarrow) or adopted and formalised one initiated by another organisation (Eastmere, Sedgeton and Whinshire). The same applied to case management schemes. *Table 3* outlines the resulting care networks. PCTs, and later CCGs, also played a part in organisationally integrating formerly separate providers.

Senior manager advocacy was a precondition for these activities. Whinshire PCT – where the most developed care network appeared – had had a Director of Integration who was a driving force and could

[S]ee the interests of all the partners and seek to identify solutions that yet didn't run against the interests of all the partners

Voluntary organisation director WP07

and had some like-minded colleagues, as had the chief executive at Tarrow. The difficulty came in sustaining this support during the conversion of PCTs into CCGs, and the concomitant staff 'churn', and during the similar 'churn' at the end of time-limited special projects to promote integration. These individuals had moved on before relationships between the organisations that had collaborated became institutionalised. After the pilot collaboration with the county council ended in Whinshire, it became:

[I]mpossible to keep track of the different boards and subgroups [. . .] the same people are sitting in four different meetings [. . .] no one knows which meeting actually has the delegated authority to decide anything.

Social care manager WP17

Managers also used techniques such as gaining Pioneer Site status and facilitating access to knowledge and examples of good practice to legitimate interorganisational working. Performance targets had mixed effects on interorganisational collaboration:

It's a system which is very much operating in flitting between 'how are we going to solve it' through to 'who are we going to blame for it?'

Social care manager WP17

For instance, the care co-ordination hub in Eastmere was required to hold a case conference for each new patient within a week of referral, irrespective of whether the necessary participants (e.g. CPNs) did (or even could) participate. This tension between organisational targets and those of the care networks was also reported in Whinshire and Fivecastles, but not in Sedgeton or Tarrow.

Clinician advocates were equally important for introducing and promoting projects and maintaining close working relationships at senior medical management levels across organisations. A GP lead explained how he had 'got the consultant on board and he very much has the same vision' for frailty care teams 'both within the hospital setting and the community' (EP19). Our study practices either maintained frequent contact with CCG leads or had them as partners (and were, in that respect, atypical).

Providers that could not be integrated had, nevertheless, to be recruited to the care networks. Eastmere CCG's experience with its mental health provider shows that this was not a foregone conclusion. All of our study site CCGs encouraged voluntary bodies that provide additional services and participate in care co-ordination work.

The CCGs also mandated, and in some instances designed, the cross-organisational care pathways that the care networks operated. Whinshire CCG constructed two reablement/recovery pathways for older people with mental health problems (e.g. dementia) to 'step down' into bedded care at either a NHS subacute service or a county council residential home with NHS in-reach mental health staff, followed in either case by a step down to domiciliary care. Sedgeton CCG's frailty pathway was a common strategy for the acute trust, CHS and general practices. The CCG wanted GPs 'to be much more responsible for a co-ordinated way for, particularly, people with complex needs' (manager SP09).

Sedgeton CCG funded two 'interface geriatricians' to co-ordinate the acute hospital and community services. Eastmere CCG introduced a scheme for designating GP leads for residential and nursing homes.

Constructing a care pathway involved defining which patients were eligible for case management, corresponding referral criteria and procedures, professions' and providers' roles, and disseminating these to all of the providers and health workers involved. The example of Eastmere shows that achieving all of this was not a foregone conclusion, either. In Whinshire, the absence of shared key performance indicators across health and social care, and the different contractual arrangements, made joint triage sometimes problematic, and even a cause of disagreements.

Commissioning played little direct part in the care co-ordination mechanisms that we observed. At the time of this study CCGs did not commission most general practices, but all of the study site CCGs used discretionary directly enhanced services to pay general practices for additional work on frail elderly, especially dementia, patients; for instance, risk assessment of 5% of GPs' patient lists in Fivecastles. Eastmere and Tarrow CCGs devolved the budget for this nursing home in-reach to those general practices that undertook it.

Paying hospitals and mental health services by tariff was not always helpful to interorganisational care co-ordination. For hospitals these tariff payments rewarded activity rather than its prevention, and were an incentive to retain caseload and services.⁵⁵ In Tarrow, we were told, tariff payments were a disincentive to accept probably high-cost patients within each tariff group. For our focal care group, 'high cost' did not necessarily reflect technology-intense treatment; only, perhaps, that transport would be costly because of where the patient lived. Similarly, for the more activity-based payments to CHS providers, a home visit by a mixed CHS team (e.g. nurse and therapist) still only counted as one visit when it came to paying the provider. Providers were at times unresponsive to contractual 'fines' for late discharges. In Fivecastles and Eastmere 'a lot of them just took the hit and took a fine' (GP EP19).

One activity that was not reported to us was the use of CCGs' commissioning powers to equalise capacity across providers for our focal care group, so as to even out bottlenecks in the care pathways (e.g. to match hospital and CHS throughput). Providers seldom pooled budgets. Previous chapters have reported the difficulties of information sharing, which applied to managerial as well as clinical purposes. We found few systems, other than 'planned' patient representation in care networks, for managers (and then, not commissioners) to capture patient stories and experiences. That said, it should be remembered that the new commissioning system was still young. Joint Strategic Needs Assessments did not yet seem to have had much practical impact on the care networks.

Paywalls for social care, and the consequent assessment of patients' needs and finances, were, as noted, widely reported bottlenecks and obstacles to maintaining flexible access and cross-sectional continuities of care. Personal budgets were blamed in Eastmere for social services producing their own care plans separately from NHS care plans. Commissioners wanted to find workarounds to ensure that day centres were not accidental victims of the personal budget system (as day centres were not easy to finance from personal budgets).

Information systems

Policy documents state CCGs' governance role as including the promotion of IT systems to support current policy goals, including sharing managerial information across providers,²² which might reasonably be taken to include standardised, shared EHRs. Whinshire had fairly integrated medical records for frail elderly patients, with read-write access for GPs, community nurses, teams and therapists, other health and social care staff, and indeed for patients and carers. If patients consented, the information collected about them became available to hospital wards. That experience provides proof of concept that such systems are feasible in NHS settings. A conspicuous absence even in these systems, however, was of mechanisms for capturing evidence of patient experience for use in designing care co-ordination.

Managerial discretion at provider level

For care co-ordination to occur, it was necessary not only for providers to join the relevant care networks, but also, as a Service Delivery and Organisation (SDO) study on networks²⁵⁸ suggested, to implement internally the networks' rules and working practices for care co-ordination. Some of our patient interviewees noticed (see *Chapter 5*) that it was one thing for one organisation to send information or requests to another, but another thing again for that information or request to reach the relevant frontline workers or the patient, or to be acted on.

For managers within care providers, care co-ordination posed various prioritising decisions and trade-offs:

1. Whether or not to target interventions at those most in need. In the rest of the county (although, curiously, not the part where our study general practices were located), Eastmere CHS concentrated its NPs on high-admitting nursing and residential homes only.
2. Whether or not to mandate attendance at interagency team meetings; in Eastmere and Fivecastles attendance was otherwise erratic.
3. Whether or not to standardise admission criteria. Different parts of the same organisation could react differently, even inconsistently (e.g. Whinshire county council therapy services had different criteria for accepting CHS and hospital referrals), in co-ordinating care with external providers.
4. Whether to trade off relational continuity of care against 'efficient' scheduling of staff caseloads by allowing staff time to travel to maintain continuity with patients who move home, or to maintain contact, as least for a while, when patients cross organisational boundaries.
5. How to trade off the use of less skilled and cheaper staff against the use of more flexible, costly, specialised and productive staff, especially in rural areas or for more complex care such as acute care at home, as discussed in comparisons of the relative costs of general medical and advanced nursing practitioners as case managers.²⁰¹
6. How to trade off larger provider scale and scope for cross-sectional and flexible continuity against a possible cost in relational continuity (although, as the corporate general practice we studied illustrates, even having a small-scale provider does not guarantee relational continuity).
7. How to trade off the presumed (although there is little published evidence) economies of case in centralising, for instance, community nursing services at local level against the informational, flexible and relational continuity advantages of collocating them at general practices.

Care co-ordination, both internally and externally, also at times confronted the obstacle of professional cultures focused on who 'owned' which part of which services, and they were distrustful of assessments and judgements made by members of other professions. Against this, we were also told that practitioners appreciated being appreciated, not least by those in other professions:

What's nice as well is you're valued, is like sometimes the GP will ring you up and they ask for you, you know, and it's one of your patients and the GP will ring up and say, '[name], I've tried this, tried that, what do you think?'

CPN EP13

Insofar as managers can manage organisational culture and climate (a moot point), such comments suggest that provider managers faced decisions about managing organisational cultures in favour of interprofessional and interorganisational collaboration. For instance, our informants valued the often small meetings that brought bits of services together and enabled them to get to know, through personal contact, who was who in the local health system and what was happening in everyday service provision.

Integration and disintegration

In Whinshire, the joint management of health and social care services had run its allotted time as a pilot project, but left some enduring legacies (e.g. the integrated information system, multiagency teams) that continued to evolve, indeed to expand to other care groups, after the project formally finished. There was, however, dissatisfaction within social care in parts of Whinshire.

Joint management of primary, acute care and county council social care had been reversed in Tarrow, with adult social care returning to county council management. We were told that the reasons were:

1. Financial: central demands for 30% cost cuts over 5 years, compounded by lack of robust financial models at the outset.
2. A protectionist coalition: the trust was not culturally integrated, but more a coalition with some protectionist members. A social care view was that money was spent on social care not to achieve social care goals, but 'short-term responses to the tier four emergency issues that [trust name] were having' (social care manager TP09) prompting social care to leave. (The same tension was reported in Whinshire.) Some other leading members were preoccupied with preserving the DGH so that the trust never 'actually broke away from the currency of the health service being dominated by the acute sector' (NHS trust manager TP01).
3. Ownership and vision: there was turnover among senior managers and non-executive board members compounded, in a site that always had difficulty recruiting (and this was not the only one in our study), by recruiting staff who instead of the integrated trust vision had more traditional, even divisive, attitudes: 'what I saw was a very traditional and very unhelpful social worker versus GP clash' (NHS trust manager TP01) and a board that, some suggested, had little experience of or support for the public sector.
4. Role and adequacy of CHS and primary care: the trust was not an implementation of, say, the Kaiser Permanente model, but based on 'a reactive, a traditional reactive primary care, not a proactive integrated system identifying patients who were at risk of admissions, intervening early, stabilising, allowing patients to continue to be independent in their own homes' (NHS trust manager TP01). 'Traditional' appeared to mean some GPs thinking 'If in doubt, I'm going to use the hospital' (NHS trust manager TP01) and (as others also thought) 'the desire to preserve professional independence and economic independence' (NHS trust manager TP01). A fundamental misalignment of incentives, structures, institutions and interests limited GP sign-up beyond the leaders (indeed, limited GP engagement with the CCG more generally): 'Almost irrespective of the financial situation, there would have come a point at which questions were raised about primary care and the interface between the new model of care we were running in [trust] and how that fits in with general practice' (NHS trust manager TP01).

5. Timing: before the banking crisis struck there was too little time to properly 'develop the relationships [...] and] develop the mechanisms [...] in terms of getting a more integrated approach it is going to take us a while' (social care manager TP09).

Certain NHS-wide governance structures also both enabled and constrained care co-ordination. The relevant higher-level governance structures were:

1. the consultation model, which is heavily institutionalised within the NHS
2. information governance regulations and law
3. paywall barriers to accessing services
4. the fact that after the 6-week time limit patients had to be financially assessed before receiving ongoing social care
5. institutionalised 'cultural' differences between professions
6. not least, the tripartite structure with its radical separation of primary medical care from CHS, and of CHS from social care.

Chapter 10 Organisational integration: public-sector example – Sweden

NHS general practices include primary medical care but otherwise provide only a narrow range of services and are small. Other primary care providers (e.g. CHS) have more extensive, varied services but exclude primary medical care. To research, empirically, what implications unified organisations providing both primary medical and community services might have for care co-ordination, we must look further afield. Of the many other health systems that have organisationally integrated primary care, the Swedish system resembles the NHS in technical capacity, health-system funding and political culture, although it is run by local authorities,^{68,69} and it has undergone neo-liberal ‘reforms’ with choice and competition.²⁵⁹ Although the most common model is a health centre (*vårdcentral*), the system contains diverse organisational forms of these, including diverse ownership. Its *vårdcentral* and *narsjukvård* centres, described below, were one source of the ‘polyclinic’ concept in English health policy (see *Chapter 1*). Given our RQs, Sweden makes an informative comparator with England in this respect.

This chapter summarises findings from the Swedish study about:

- the Swedish context – the organisational varieties of integrated primary care provider in the country
- its mechanisms for care co-ordination (i.e. for producing the continuities of care), following the schema in *Chapter 2*
- survey evidence as to how the different organisational types of provider significantly differ in the care co-ordination mechanisms they use, and some consequences of these differences for patients.

The chapter closes with a comparative discussion of lessons from Sweden for the UK regarding co-ordination and integration. *Chapter 4* has already reported the methods used in the Swedish element of this study, but essentially we compared aspects of primary care provision in Stockholm – which, compared with most other counties in Sweden, has a greater mix of models, including those described below – with Sweden as a whole. Our 2011 survey of all the PHCCs in Sweden suggests that, in Stockholm, 25% of primary care providers are in private for-profit ownership, which is probably higher than for the rest of Sweden.²⁵⁴

Six PHCCs were selected for their different organisational structures and ownership:

1. Liseberg: public, salaried doctors.
2. Norrtälje: not-for-profit ‘public firm’ with salaried doctors.
3. Ostra: part of a not-for-profit private company owned by doctors in partnership.
4. Djursholms läkarmottagning: public, with salaried doctors.
5. Solna-Capio: corporate, with salaried doctors.
6. Stockholms Sjukhem primary health-care service: part of a larger not-for-profit private foundation, with salaried doctors and one primary care doctor-centred primary health-care service based at a hospital.

All are funded by SLL, as described below, but SLL directly manages only Liseberg and Djursholms läkarmottagning.

The primary care system

Before 2006 there was almost exclusively public (county local authority) provision of primary care. The *vårdcentral* PHCCs were geographically organised. Both primary care doctor (*primärvård läkare* or *husläkare*) and nursing home care services were provided. Patients who lived in a PHCC geographical catchment area were assigned to that centre. Certain PHCCs offered emergency doctor services at evenings and weekends but not publicly funded out-of-hours home visits by doctors. In cities like

Stockholm, patients who have money could buy some private services (e.g. nursing, social services, home care) to supplement or replace public services. Social services were normally provided by municipalities (municipalities are smaller local authorities and separate from but encompassed within the larger counties). As in England, Swedish citizens co-paid for social care when they were over 65 years of age, and the assessment of individuals' social care needs was separated from service provision.²⁶⁰ Home care could be ordered by a doctor, nurse or welfare officer.

From 2010, counties were mandated to adopt the *Vårdval* ('choice of care') system, including a choice of primary health-care providers,²⁶¹ which is said by some²⁶² to favour bigger and/or horizontally integrated providers. Under this system:

- Patients can choose their PHCC from a published list, and can change it. Patients tended to remain with their local primary care centre, but a few chose one some distance away.
- Organisations (including private and not-for-profit companies) that met basic requirements about medical competence and the basket of services they provide could register as primary care providers. As in the UK, organisations rather than individual professionals were the provider-site party to contracts with health-care commissioners.

All providers are paid from public budgets, supplemented by patient copayments that are the same for all providers and limited to SEK1400 (€153/£121) per patient per year. (Some categories of patients are exempt.) Providers are paid on a capitation formula plus specific payments per patient visit. However, county councils may vary the formulae, some adding quality measures, access and activity targets and attaching financial incentives to them. There are, generally, no direct financial incentives for interorganisational collaboration.

Independent co-operatives of doctors and, increasingly, branches of a few large private companies coexist with publicly owned polyclinics. Our national survey showed a decrease in government ownership in the sample (69% in 2011 vs. 79% in 2005) and an increase in private for-profit ownership (25% in 2011 vs. 8% in 2005). Although our response rate was 37%, these figures are consistent with other study findings^{262,263} and are as expected given the 'choice' reforms. Nationally, 15–20% of all primary care is delivered by for-profit nationwide chains. In addition, the clinician-owned *Praktikertjänst* (see below) has, overall, a 15% market share. Physician groups own some companies. About 1000 'private' doctors nationally also provide care on a fee-for-service basis. Some areas have individual or group private practices, similar to the UK model of general practice, and private therapists. In all, county councils own and run circa 50% of primary care. Over the past 10 years, there has been little real increase in primary care funding (still circa 10% of health budgets) or in the number of primary care doctors (approximately 15% of the medical workforce).

Public polyclinics and care co-ordination

The variety of organisational models is greatest in Stockholm, where we considered six examples, taking three (Lisebergs Vårdcentral, Djursholms Läkarmottagning, Kista Vårdcentral) that were owned and run by SLL for more in-depth study. Djursholms Läkarmottagning employed six doctors (one part-time) and four district nurses. Lisebergs Vårdcentral served 8500 patients registered with doctors at the centre, and patients at a care home for older people and two homes for disabled people. About 1000 of its registered patients lived outside this centre's geographical catchment area. Kista had 13,500 listed patients (60% of non-Swedish background) and provided services to two nursing homes and eight homes for disabled people.

Care co-ordinator

Having chosen a PHCC, patients are assigned a primary care doctor, whom they can change. In practice, they may have to wait to see their chosen doctor, so many simply see the first doctor who is available. At Kista, patients also had an assigned lead nurse.

The consultation model of care co-ordination predominates. Typically, the doctor will transfer the patient to the polyclinic-employed or -based nurse. Referrals to a physiotherapist, a speech therapist, an OT or diagnostic service must be made by a doctor if that consultation is to be publicly funded. Polyclinic-based nurses cannot refer patients directly to a specialist or therapist, but must either ask the doctor to do so or ask the patient to ask the doctor. Most PHCCs say that one of their nurses 'co-ordinates care', especially for complex cases, but the amount of co-ordination done by the nurse varies between centres and none operates a formal care manager model. As noted, nurses cannot refer directly to specialists or other professions. Our survey²⁵⁴ suggested that case management schemes were not widely used. Only one-quarter of PHCCs responded using case management for diabetes, and much lower proportions for other chronic diseases. Where case management is used, it is generally underdeveloped, underspecified and subordinated to the consultation model of care co-ordination. No one else provides such a service instead, in which case this low use is significant for generating high costs and reducing quality of care, especially for heart failure patients.

There is a more systematic care co-ordinator role in some mental health services. A psychiatrist or nurse 'case co-ordinator' will invite others to a needs assessment and care-planning meeting. In one area in Stockholm (Sodertälje), a psychiatric care co-ordinator and a municipality case manager will work together, each co-ordinating other personnel from their respective health or municipality services. When these co-ordination responsibilities are defined, the specification is of the very general job; authority and accountability are not sharply defined. Again, neither can refer directly to other specialists.

Care plans

All patients have a doctor and nurse care plan, but there is variation between patients and between professionals in how much the patient is involved and decides on the plan contents or services to be used. The doctor and nurse usually consult patients about whether they want or need different services, and patients can ask for a service professional to be changed. Beyond this, patients have little choice as to when the services are provided or other details (e.g. when home care or meals are delivered).

Services and specialisation

At Lisebergs Vårdcentral, five primary care doctors, two trainees in general medical practice, six district nurses and two speech therapists provided services. A neurologist routinely provided outreach sessions. Djursholms Läkarmottagning had six doctors and four district nurses but no specialist outreach clinics. No private practitioner services or social service staff were based there. Kista had nine family doctors, five 'residents' (consultant equivalent), two trainee doctors, an outreach geriatrician clinic, seven district nurses, six unqualified staff and extensive physiotherapy services. A privately owned diagnostic laboratory was colocated there.

Vårdcentral nurses generally provide both 'basic' and 'advanced' (e.g. palliative) home nursing services and services at the centre itself. They visit patients at home within the defined area, and outside the area if not too distant, provided that the nurse deems the patient to be a 'home care patient'; that is, somebody who needs nursing services more than once every second week. If they need nursing services less frequently, Liseberg Vårdcentral will not provide them, but this criterion was decided by Liseberg Vårdcentral itself and not by the county council, and no other *vårdcentral* adheres to it. In general, the nurses at each polyclinic can set their own local criteria for prioritising and scheduling home visits. Officially, *vårdcentral* nursing services are provided equally to all registered patients, whether local or distant, but in practice nurses appeared not to visit the more distant patients outside their area. Details vary, but typically a nurse will work a week at the *vårdcentral* clinic itself and then make home visits for the next week. It was not clear to us whether or not nurses also made home visits to patients who were inside their area but registered with other polyclinics. *Vårdcentrals* also undertake population-oriented public health activities such as maternity and well-baby clinics, vaccinations and care in the community.

Therapists (physiotherapists, OTs, speech therapists, clinical psychologists) were based at certain polyclinics, but were managed by therapy managers rather than the polyclinic manager and provided services to a wide area, although some did also provide regular sessions at the PHCC where they were based. Some (but not all) PHCCs shared a building with a laboratory and specialist outpatient departments. There is no separate out-of-hours service like in the NHS. ED visiting rates are high.

Co-ordination mechanisms within a single organisation

Vårdcentral PHCCs have a hierarchical organisational structure in which the doctors, nurses and (in some) therapists employed are managed in one unit and subdivided into MDTs. All personnel, doctors included, are employed by the county council, which also owns and manages the building. Each *vårdcentral* has for its manager a clinical director (usually, but not always, a doctor), who has limited discretion over expenditure within defined budget headings. This clinical director reports to a co-ordinating director, who in turn reports to the director of the Stockholm county division of primary health care and mental health.

The *vårdcentral* director ‘manages’ the other doctors in it, as also occurs in the private PHCCs. The key issue, however, is what ‘manage’ and ‘line manage’ mean, particularly regarding clinicians’ scope for clinical autonomy, which is pre-defined (constrained) by various policies, procedures and clinical guidelines. The *vårdcentral* director has ‘management autonomy’; that is, authority and scope to decide management issues. In practice, management autonomy is fairly limited. The doctors have medical (clinical practice) autonomy in the sense of latitude to make treatment and clinical decisions by themselves without checking with anyone else, but only within the aforementioned policies and procedures. Managers’ decisions can be reviewed and over-ridden by a higher authority, but doctors’ decisions taken in exercise of their clinical autonomy rarely are. Notwithstanding the salaried status of (most) Swedish primary care doctors and the independent status of (most) English GPs, the clinical autonomy of Swedish polyclinic doctors remains less constrained than in the UK.

As noted above, MDTs are usually formed among the staff working (and mostly, line managed) within each polyclinic. However, there is no one standard model, and generally there are informal working arrangements between personnel, apart from the formal referral arrangements noted above and the employment role descriptions that specify the work of employed staff.

All authorised employed health personnel (licensed professionals) at the polyclinic have access to some common patient data stored by the *vårdcentral*, but not to all data held in the patients’ EHR. Polyclinic doctors have access to a patient’s EHR and electronic medical record (EMR, a subset of the EHR) showing the patient’s history, tests, diagnosis, treatments and referrals, and to the polyclinic’s nursing record containing the patient’s nursing needs assessment and care plan. Parts of the patient’s record (e.g. the care plan) can be shared with social services and private providers, but only with the patient’s consent. Most polyclinic doctors do not have access to the patient’s hospital EHR or EMR, but do have access to tests, diagnostics (e.g. radiology) and discharge reports.

Privacy laws forbid patient data being communicated between municipality and health-care IT systems, although this position is currently changing. In the meantime, there is no common case record. Neither may patient data be shared between the polyclinics and, for instance, private nursing homes or private home-care services, although in these cases it is also because the record systems technically cannot exchange data. At present, patient information is also not fully shared between the polyclinic, the hospital and other authorised health-care providers. (There is no shared EHR.) In Stockholm, and most other regions, one health IT system that does enable co-ordination and collaboration between patients and their care providers is *Mina vårdkontakter 264*, an encrypted service for patients to access and help co-ordinate their own care. This enables patients to contact services electronically; add notes about scheduled doctor visits, immunisations and more in a calendar; and get text message or e-mail reminders on the day before a visit. Patients can access their personal health record and, in some cases, contribute to it. Nevertheless, at present the system is too complicated for many patients to use.

Vertical co-ordination

Formally, patients can also choose their hospital. The patient choice policy is being extended to elective surgery, allergy testing and other specialist services. Patients usually choose on the basis of distance and travel times (which may limit their choice), primary health-care doctors' recommendations and those of friends. As in England, patients have no direct access to specialists, who are mostly employed by the public hospitals. All PHCCs are gatekeepers to secondary care. In most polyclinics, formal systems for all the above are less standardised and developed than in the NHS, apart from agreements (clinical guidelines) about when it is appropriate for primary care doctors to refer patients to specialists. Most hospitals send discharge notifications electronically to the polyclinic and the referring doctor, and notify municipality social services. If the patient is 'medically fit for discharge' but cannot be discharged because the municipality has not made arrangements, the municipality is charged for each day the patient remains in hospital. However, this 'fine' is sometimes lower than the cost to the municipality of arranging nursing home or home care. *Når sjukvard* health centres are larger, and are also publicly funded and managed. They are run by local hospitals typically offering planned day surgery, other day treatments and limited inpatient care besides the primary care described above.

Norrtälje södra vårdcentral

Other organisational variants have developed alongside the publicly owned and managed polyclinics described above, but all providers, at least in Stockholm, face almost identical contractual requirements regarding what services they must provide for patients (see previous section).

Norrtälje has combined an integrated local health and social services provider with a commissioning function jointly representing Stockholm county and Norrtälje municipality. The whole organisation has a political joint governing board (six municipality and six county politicians) responsible for both health and social care to the municipality's population, and with the right to appoint and dismiss the chief executive officer of TioHundra AB (see below). An integrated financial administration (TioHundra Forvaltningen) administers the combined (pooled) budgets for all health and social care, and the still-separate welfare payments budget. It also executes board policy, collects payments from different sources and pays providers. From 2008 the administration commissioned a single publicly owned not-for-profit company, TioHundra AB, to provide integrated primary care, hospital and social care services for the whole population. This governing body, the purchasing administration body and the integrated provider that links them are together termed the 'Norrtälje Integrated Organisation' or 'Norrtälje model'.

Norrtälje PHCC was part of a provider that also ran a hospital and mental health services (about 85% of health services for the Norrtälje population), with a budget shared across them. SLL and Norrtälje municipality jointly let the buildings that TioHundra AB uses to the provider. The PHCC director is accountable to the head of primary health care within TioHundra for the administration of the centre, and manages the primary care doctors employed there. The PHCC has four primary care doctors, four trainees, eight district nurses and four speech therapists, serving registered patients who mostly live in the surrounding area. The *vårdcentral* also provides home-care nursing services for up to 2 weeks after a discharge from hospital. A separate community nursing and social care service provides home care services thereafter and for other patients. The district nurses working at the centre are managed by the centre director (a nurse), but employed by a separate joint nursing and social services division within TioHundra AB.

The integrated organisational structure was reported as making it easier for operational managers to make clinical-level ('micro') changes to improve co-ordination.³³ These micro-changes included having one manager for both geriatrics and elderly care; managing services on a care group rather than occupational basis; individual care planning with a preventative focus; and a more co-ordinated patient pathway for stroke patients. Eleven largely isolated information systems containing individual patient data were reduced to two. Implementing these micro-changes still required further effort in the face of occupational concerns to 'protect' work demarcations and autonomy, staff perceptions of the extra time needed for co-ordinating care, and the inherited profession- and service-based communications and records systems.³³

Other variants

Norrtälje apart, the differences between the conventional *vårdcentral* and other PHCCs are mostly in relation to the providers' ownership, management and exact combination of services provided, rather than the care co-ordination arrangements described above.

Östra Vårdcentralen

This service is owned and run by a private for-profit company, a partnership of eight GPs. The PHCC clinical director (one of the doctors) is accountable for centre services and budgets to a board of directors, that is, the other seven doctors. The doctors' company employs the nurses, who provide home-care services to registered patients and to a home for disabled people. The doctors rent the PHCC building from SLL. In it are colocated other council-run services: a laboratory, a hospital, psychiatric services, a hospital outpatient gynaecological clinic (*mottagning*) and a geriatric clinic. A radiography service, orthopaedic service and private pharmacy are also colocated there, but there are no social services, hospital specialist clinics or private practitioners.

The doctors buy managerial support services from a larger partnership, Praktikertjänst AB, of which 'Our 2000 shareholders are dentists, dental technicians, dental hygienists, physicians, physical therapists/physiotherapists, psychoanalyst/therapists, psychologists, nurses, midwives, speech therapists, occupational therapists, social workers, chiropractors, nutritionists and other health care practitioners who are themselves responsible [i.e. professionally registered] staff and working in the company.'²⁶⁴ To these shareholders, Praktikertjänst distributes profits. It employs another 6780 people (in 2014) and provides private dentistry (circa 30% market share) and primary medical care (circa 20% market share) besides publicly funded primary health care. It centralises managerial support services in pursuit of economies of scale, but provides primary care through numerous 'small-scale' clinics (which tend, however, to be larger than most English general practices).

Stockholms Sjukhem

This PHCC is owned and run by the not-for-profit private foundation Stockholms Sjukhem. A doctor is clinical head of the unit, accountable to the foundation's director. Based in the grounds of a hospital, a PHCC with two doctors and one district nurse serves a list of registered patients. No social services, hospital specialist clinics or private practitioner services are colocated there. Stockholms Sjukhem has a contract with the county council to provide the primary care doctors, and employs the doctors and the nurse. The wider foundation within which the centre is incorporated also provides district nursing services ('Advanced Care in the Home') and a rehabilitation centre, nursing home and memory clinic (which also provides home visits by OTs). Rehabilitation services are accessible without referral for primary care patients (but a hospital doctor's referral is required for hospital discharges). Palliative care is accessed by referral; other nursing home care is not.

Solna Vårdcentral

This PHCC is one of nine in Stockholm run by Capio AB, a corporation leasing the building from a public construction company. It contracts to SLL to provide primary care (specified by the 'rule book' – 'what we should do, and how this is checked') between 08.00 and 22.00 on weekdays, with evening cover at the nearby SLL Solna Vårdcentral. The centre's income depends on the numbers of patients registered and patient visits, but the per-visit payment decreases once the average number of visits per patient per year exceeds 1.9. Capio's district nurses provide home nursing to home-care patients. Assistant nurses provide home-care services (*hemtjänst*). Social care assessors (*biståndsbedömaren*) arrange separate home services and personal care services from the county or municipality.

To co-ordinate care for some patients, the PHCC district nurses needed to co-operate with the social care assessors. Both parties considered themselves care co-ordinators, but there are no formal systems to ensure co-ordination, which does not always occur but is more likely to do so if the following apply:

1. The different services cover the same patient population or nearly so (often similar geographical areas). Then, the Capiro nurses are likely to be repeatedly in contact with others caring for the same patients and to care for other patients that they have in common.
2. Continuity of personnel.
3. Good personal relations between staff.
4. Staff are not overworked and hence do not tend to pass tasks on to others when the option arises.
5. There are stable systems (e.g. telephone numbers do not change) for faxing, telephoning and exchanging information. In acquiring another firm, Capiro also acquired its electronic 'deviation' (adverse event reporting) system, which was initially not interoperable with Capiro's own.

Most interviewees thought that a well-defined care co-ordinator role would improve care for patients who needed multiple services and would avoid conflict and duplication or missed services, but that it would require funding.

Survey findings

Organisational characteristics

In Stockholm, where a higher proportion of PHCCs are privately owned and/or managed, nearly 20% more patients were registered for each centre (10,400) than for the Sweden sample (8500). The mean number of doctors was 30% more and nurses nearly 50% more per polyclinic.

Fewer Stockholm heads of polyclinics than those in the national sample reported experiencing a favourable financial impact from investments to improve quality of care for four chronic diseases (coronary heart failure, depression, diabetes and asthma). Thirty per cent reported a positive financial impact for investments in raising the quality of diabetes care compared with 34% for the national sample, and 4% for heart failure improvements compared with 13% nationally. Equally, however, Stockholm centres were less likely to report negative financial impacts (2% Stockholm vs. 4% Sweden). In both Stockholm and elsewhere, 60% and 64%, respectively, of PHCC heads reported that their centre had undertaken no financial investment in quality improvement for heart failure. Significant differences between centres in the Stockholm sample and those nationally were greater in respect of information systems:

1. 9% more Stockholm PHCC heads said that they made reports to another organisation about their adoption or use of IT (36% vs. 27% for all of Sweden)
2. 23% fewer in Stockholm said that they had a patient discharge summary available (70% vs. 93%)
3. 27% more in Stockholm said that they had laboratory results available electronically (94% vs. 67%)
4. 10% more had warnings of potential drug interactions (80% vs. 70%)
5. 8% more had reminders at the point of care (46% vs. 38%)
6. 4% fewer had some e-mail contact with patients (47% vs. 51%).

In Stockholm, where a higher proportion of polyclinics were privately owned than elsewhere:

1. Fewer sent patients reminders for preventative or follow-up care. Fourteen per cent fewer did this for diabetes than in Sweden as a whole (25% of PHCCs vs. 39%), 12% fewer for coronary heart failure (27% vs. 39%), 9% fewer for depression (22% vs. 31%) and 20% fewer for asthma (25% vs. 45%).
2. Fewer non-medical services were used, especially for coronary heart failure, which was 19% less than the national average (14% vs. 33%). For diabetes it was 5% less, for depression it was 11% less and for asthma it was 14% less.

3. Less use was made of case management for coronary heart failure: only 4% of PHCCs in Stockholm reported doing so, compared with 8% nationally. Otherwise there were few significant differences between Stockholm and the national pattern. Nationally, only 26% of sites used this proven practice for diabetic patients, 17% used it for asthma and none used it for depression.
4. More doctors received guideline-based reminders about which services patients should receive. According to patients' EMRs, such reminders were used in 7–11% of Stockholm PHCCs, compared with 5% across Sweden generally. Again, however, even the top figures were low.
5. More PHCCs had lists of patients with the four diseases (coronary heart failure, depression, diabetes and asthma) than in the national sample. The largest significant difference was that 12% more Stockholm centres had lists of patients with coronary heart failure (68% vs. 56% for all of Sweden).
6. More PHCC heads reported giving feedback to their physicians about their quality of care: 14% more used this for quality of care indicators for coronary heart failure patients (38% vs. 24% for all of Sweden) and 11% more used it for diabetic patient quality indicators (60% vs. 49%).

The above patterns appear consistent with the hypothesis that where there is a higher proportion of privately owned and/or managed polyclinics, informational continuity within the polyclinic is higher than elsewhere, but external informational continuity and case management (longitudinal and flexible continuity) are lower.

Care co-ordination and integration in Swedish primary health care

In Sweden, much was achieved for continuity of primary health care by the creation of *vårdcentral* polyclinics. At present, the most significant areas for improvement are to strengthen these areas:

1. case management for heart failure
2. availability of hospital discharge information on the patient's EMR screen at the polyclinic
3. patient reminders for preventative or follow-up care
4. providing non-doctor support to patients in managing their condition.

Comparing the above with care co-ordination in the NHS, implications for the NHS (RQ 5) appear to include the following:

1. Constraints on primary care doctors' exercise of clinical autonomy are not necessarily more restrictive when those doctors are salaried public employees than when they are independent contractors or partners. In both systems, clinical practice was managed largely through guidelines and clinical audit.
2. Swedish polyclinics give proof of concept of the feasibility, in a NHS-like setting, of combining the management and delivery of primary care medicine, therapies and district nursing – often together with one or more of rehabilitation, social work, nursing homes, memory clinics, psychological therapy and dentistry – within one organisation. Commonly, district nurses and/or social workers were managed in a separate hierarchy from doctors and other polyclinic staff, the two hierarchies coming under a common manager at a higher organisational level. Polyclinics were often somewhat larger than most English general practices, although smaller than the largest NHS general practice with its 40 whole-time equivalent doctors.²⁶⁵
3. Scope for managerial discretion (RQ 3) was constrained not by the organisational structures so much as by relationships between non-medical management, medical managers and non-manager clinicians that in many ways resembled those found within NHS trusts before, say, 1997.

4. Organisational integration mitigated, and in some cases removed, the following barriers to interorganisational care co-ordination (RQ 1):
- i. Interorganisational barriers to information sharing. Management information was generally (but not completely) standardised and available across different services. The remaining barriers, within polyclinics, reflected differences in different professions' roles, culture and status, and technical underdevelopment.
 - ii. Tension between the care pathways implied by nurse-led case management and the consultation model, which was, in Sweden, resolved in favour of the consultation model. Conceivably, this tension could have been resolved the opposite way, but in any event the work of constructing and operating additional interorganisational care networks and their co-ordinating bodies alongside the primary care doctor's co-ordinating role was unnecessary (and not observed).
 - iii. Administrative 'round trips' from another provider to the general practice and back again to obtain budgetary authorisations.
 - iv. Even though pooled budgets (where they existed) removed financial obstacles to referrals, some administrative barriers (e.g. social care assessment) remained.
 - v. Mismatched financial incentives and managerial targets between different provider organisations.
 - vi. Separate locations of primary medical and district nursing services and their staff.
Removing these barriers did not make care co-ordination completely unproblematic, but the remaining problems of both horizontal and vertical co-ordination were similar to those that might be found within a NHS trust (above all, dealing with strong, somewhat separatist professional cultures; geographical separation of services).
5. The difference that ownership made (RQ 2) was most apparent when a provider changed ownership and had to become integrated into another organisation with different managerial practices and IT systems. During the transition period the integrated organisation still retained many network-like characteristics (especially regarding the availability and uses of monitoring information).

Chapter 11 Conclusions

Summary empirical findings

We summarise our empirical findings by RQ.

Research question 1: integration versus network

Research question 1a: horizontal integration, hierarchy and networks

We compared two partly horizontally integrated trusts (CHS with mental health in Whinshire and CHS with social care during the earlier period of the Tarrow site) and Swedish PHCCs (all to varying extents horizontally integrated) with care networks. Following a falsificationist methodology, we first present findings against our initial hypotheses (see *Chapter 2*) that integrated organisations containing a wide range of services (above all, primary medical care) are more likely than care networks to favour the development of care co-ordination and continuity of care.

Certain horizontal care co-ordination mechanisms that we found in the integrated organisations were also present in at least one care network:

1. consultation model of care co-ordination with:
 - i. primary care doctor as the *captant* professional
 - ii. case management
2. interdisciplinary care teams (often several in parallel)
3. 'virtual ward' or 'hospital at home' models of care, although often with patchy coverage
4. integrated electronic patient records to which different professions have read–write access (with varying degrees of access and duplication)
5. colocated services.

The following obstacles to care co-ordination were found within integrated organisations:

1. professional silos, with rivalries and self-imposed isolation of occupational groups
2. discrepant IT systems for different divisions or care groups within one organisation
3. non-medical case management that was less developed in the hierarchical primary medical care providers we studied than in the networks
4. legislative restrictions in Sweden on record sharing between PHCC and municipality, and hence social care, although this position is changing.

Obstacles 1 and 2 were also present in the care networks that we studied.

Other obstacles to continuity of care were found in both networks and integrated organisations, but cannot reasonably be attributed to governance structures. Staff shortages, an obstacle to maintaining flexible and cross-sectional continuity, reflected austerity policy. Some health workers had an uncommunicative personality. Patients' inclinations and private resources for co-ordinating their own care varied. Discrepant working practices were found, even within one manager's span of control, which reflected different technical tasks (e.g. maintaining tissue viability vs. managing heart failure).

However, within the care networks that we studied, the following barriers to care co-ordination remained:

1. Information flows were incomplete and often laborious to maintain (and the same occurred in Sweden). SDO-funded studies of NHS networks^{258,266} did not discover much development of information systems to help care co-ordination and little seems to have changed.
2. Mismatch between care pathways and the consultation model, particularly when patients are discharged from hospital.
3. Paywall barriers (means testing), which created bottlenecks.
4. Capacity mismatches between successive providers in the care process.
5. Weak or absent interorganisational links.
6. Mismatched financial incentives and managerial targets.
7. Organisational separation, which often meant separate locations.

The more interorganisational boundaries there were, the greater these problems became. The smaller the scale and scope of primary medical care services, the more likely it was that patients who required intense or complex care had to be referred to external providers, and the greater the number of interorganisational interfaces that had to be negotiated. The same applied when multiple care networks had sedimented²⁶⁷ over time. In these respects our findings converge with some of those in the evaluation of London polysystems.⁴⁸

In our study sites, organisationally integrating services within one organisation aided in care co-ordination in the following ways:

1. Creating line-managerial accountability for achieving the co-ordination of care, for example through multidisciplinary project teams within each organisation. Every NHS trust we studied took such initiatives. Subsidiary managerial efforts to reduce the impacts of professional silos on cross-sectional and longitudinal continuity of care were also apparently needed (see below).
2. Once a patient was within the care of a provider organisation, subsequent ad-hoc transfers between professions, between specialities, between acute and community beds, between inpatient and domiciliary care and between health and social care were reported usually to be easy, flexible and swift compared with equivalent referrals across interorganisational boundaries. The same was true of Swedish polyclinics. Other studies^{142,268} suggest that increasing the range of services (scope) was more important than merely adding doctors for maintaining 'family-centred care' and improving quality of care.
3. When the same organisation provided several types of service (medical, nursing, therapy, etc.) they were colocated by default, although the 'location' might be a locality with staff working across it. In care networks separate location was the default. In those cases, colocation had to be specially negotiated between two or more independent organisations.
4. Information governance differences between organisations were avoided, removing a juridical (but not the technical) obstacle to informational continuity. In the Swedish polyclinics (where the PHCC and not the county counts as the 'organisation' for information governance purposes), primary medical care, community nursing and therapies shared medical records. The remaining barriers within PHCCs reflected differences in professions' roles, culture and status, and technical underdevelopment.
5. Linkages and working practices for transferring patients between services could still be disrupted by one service unilaterally withdrawing from an organisation unified by secondment or joint management, where services still had their distinct statutory status. Secession was less feasible for services that were built into an integrated organisational structure.
6. Providing clinic-based and home visits from the same organisation (*vårdcentral*) appeared to facilitate flexible, cross-sectional and longitudinal continuity of care.
7. The administrative overheads of indirect referral routes and care network management in addition to provider management were avoided.
8. Overall goals and external incentives were aligned across all services within the provider.
9. Provider income was in effect pooled, so that decisions about care pathway design within the provider could be made on other grounds (e.g. continuity of care) than the allocation of income between organisations.

On balance, therefore, the horizontal care co-ordination processes within the integrated organisations appeared to be more favourable to producing the continuities of care than were care network structures.

Research question 1b: vertical integration, hierarchy and networks

With adjustments, analogous findings and conclusions apply to vertical co-ordination. We found certain additional care co-ordination mechanisms, this time for vertical co-ordination, in both the integrated organisations and one or more care networks:

1. 'front-door' triage of patients coming into ED
2. integrated electronic patient records, to which hospital and primary health-care professions have read-write access (provided that patients consent to this).

Certain obstacles to vertical care co-ordination were found in both integrated organisations and care networks:

1. The consultation model required, in some cases, referral via a GP, and not direct referral from non-medical clinicians to doctors employed by the same organisation.
2. On discharge from hospital, responsibility for the patient returned formally to the GP, but in practice this responsibility often went to CHS (whose care was often more immediately needed than that of the GP). Here, the consultation model did not match the typical care pathway for patients needing intense and/or complex inputs to care after discharge.
3. Even in the Swedish *vårdcentral*s there was little sharing of medical records between primary care and hospital.

The remaining barriers and mechanisms for care co-ordination were similar to those for horizontal co-ordination of care. On balance, therefore, the integrated organisations also appeared more able to accommodate vertical care co-ordination processes, and therefore to producing continuities of care, than did care network structures.

Research question 1c: cost information

Clinical Commissioning Groups reimbursed general practices or gave them budgets for additional care co-ordination work. To that extent the CCGs quantified these costs, although more by administrative fiat than on the basis of detailed cost information.

Either themselves or via their CCG, general practices hold budgets for paying external ('second-responder') providers, according to either a DRG-like tariff (the Healthcare Resource Group) for most acute hospital and some mental health care or, for most other services, cost-and-volume contracts (block payment with marginal adjustments for activity levels). Despite general practices' recently enlarged commissioning role, the ones we studied had neither the means nor any reason to identify the overall cost of care for patients receiving care from several external providers. Indeed, it is doubtful that the cost data available to them could have yielded such information. Neither, therefore, were they in a position to identify any costs or savings attributable to better co-ordinated or more continuous care. These payment systems are standardised across England, and so this pattern may be typical of the wider NHS.

Although the Whinshire and Sedgeton care networks were in financially 'challenged' or 'stressed' local health economies, these (and the other) care networks paid more attention to 'real-side' care co-ordination than to cost information about it. They, and their member organisations, accepted the assumption that patients with frequent unplanned admissions were likely to be high-cost patients, but had little information about the total cost of care across multiple providers for individual patients, or at least care groups. Such cost information was held piecemeal within the participating provider organisations, although the availability even of this cost information depended on the extent to which tariff payments were used.⁵⁵ Hence, the care networks were not well placed to know whether or not their care co-ordination mechanisms (e.g. case management, MDT, etc.) saved costs compared with previous (or no) care co-ordination methods, or which co-ordination mechanisms did lead to cost savings.

In this respect, integrated organisations (both hierarchies and professional partnerships) and the care networks were similar, but in order to assemble the aforementioned cost information, the care networks also depended on their member organisations supplying it.

Research question 1d: diversity of services

Both for integrated organisations and for care networks, the simplest way, in the short term, to gain access to additional services for their patients was to either colocate or subcontract these services, as our general practices did for social support and leisure (exercise) services, respectively. As we have seen, however, these network mechanisms came at the price of certain obstacles to care co-ordination, compared with organisational integration. Whether or not integrated organisational or care network structures were better adapted to gaining patients access to a diverse range of services (by implication, improving the flexible and cross-sectional continuities of care), therefore, appeared to depend on the scale and duration for which this access was required. For small numbers of patients and/or short-term access, a care network structure was suitable because it was more flexible. For longer-term and larger-scale access, extending an integrated provider organisation (as our study general practices did to incorporate pharmacist support or minor surgery, or including community nursing and therapies in the Swedish polyclinics) became practicable and reduced the obstacles to care co-ordination. Further research is required to specify the scale at which the balance of advantage shifts.

Research question 2: ownership

The corporate general practice in England had low relational continuity of care despite being a small practice (which ordinarily may have greater relational continuity^{75,269}), because its doctors were part-timers with other activities elsewhere. Although this practice was more willing than others to refer its patients to self- (or insurance-) paid private care, its patients had no easier internal access to other services run by the same firm; referrals were required just as if the doctors worked for another organisation. In contrast, the corporately run Swedish PHCC did give its patients access to the CHS that the firm also owned, which were organisationally integrated with its primary medical care service. Its English counterpart appeared to make less use of external CHS and, therefore, of any case management or other services that they supplied. It had been financially unable to provide personalised care in-reach to nursing homes. Our English and Swedish data were both consistent with the hypothesis that privately owned and/or managed primary care providers tend to have greater informational continuity of care internally, but less externally (to patients and hospitals).

The professional partnerships in England were distinctive in giving their partner-doctors flexibility to develop their own interests or specialisations and latitude to refuse projects, and in their generally smaller scale and scope than the Swedish PHCCs (but not smaller than the corporate English general practice).

Both of the Swedish general practices run by social enterprises (one charity, one health worker owned) gave ready access to other services run by different branches of the same organisation. In Sweden, the integrated, publicly owned PHCCs also gave patients direct access to other services run by the organisation (with external referral), and typically provided a wider range of services than the English general practices, however owned. Except for the clinic director, their doctors had no equivalent to the practice management workload of English partner-GPs.

In summary, ownership differences in this sample of providers affected the range of services to which patients had direct access, primary care doctors' managerial responsibilities (relevant to care co-ordination because of its impact on GP workload) and the scope for medical innovation.

Research question 3: managerial discretion and performance

We found little difference between integrated organisations and care networks in terms of managerial discretion and performance. A larger difference was between NHS and Swedish primary care organisations. These differences reflected varying assumptions about the demarcations between managerial and medical jurisdiction, and the transparency of medical practice to managerial scrutiny. In these respects, the Swedish PHCCs resembled NHS practice some years earlier.

Senior manager advocacy was a precondition for activities both to establish care networks and to amalgamate the managerial structures of previously separate services (Whinshire and Tarrow). Clinician advocates were equally important for introducing and promoting projects and maintaining close working relationships at senior medical management levels across organisations.²⁷⁰

As more concrete managerial practices that promoted care co-ordination or substitution of primary for secondary care, patients and health workers mentioned:

1. Patients seeing the same GP or other clinician as far as possible, for relational and cross-sectional continuity, for example by deploying a patient's 'normal' health worker for home visits even if another worker takes the initial request.
2. When (1) is not feasible, team members cross-briefing each other about the patient (e.g. by 'live handover').
3. Ensuring that patients know what to do and whose help to seek in a crisis or exacerbation.
4. Overall care plans, from which individual providers or unidisciplinary plans follow.
5. Ensuring that hospitals can effectually refer patients directly to CHS.
6. Informing patients that their care has been reviewed (if the patient was not present).
7. Whitelists of vulnerable patients who are prioritised for access to professionals (for relational and cross-sectional continuity) and for care plans.
8. Regular audit and follow-up reviews of recently discharged and other vulnerable patients.
9. Opening health records and care plans, as far as possible, to other providers caring for the same patients.
10. Interoperable intermediate care team (e.g. conforming to open standards for data sharing).
11. Hosting or outpostting services, or seconding staff, to achieve colocation.
12. Allowing time and stability for working relationships to develop across organisations.
13. Mandating staff participation in interagency and interdisciplinary care teams when necessary.
14. Education, training and culture management to breach interprofessional 'silos' and promote interorganisational working.

We accept that in times of austerity and high GP workloads some of the above may seem counsels of perfection. To that list, therefore, we add reducing GPs' non-clinical workload by delegation to other clinicians or managers, which the feminisation of, and the looming recruitment and retirement 'crises' in, the GP workforce will also necessitate.

Research question 4: predicted differences between integration and networks

Wider implications of this research for organisational theory and other disciplines will be addressed in future peer-reviewed publications arising from this project. Here, we focus on the main hypothesis arising from our overview (see *Chapter 2*) of earlier research: *an integrated organisation containing a wide range of services (above all, primary medical care) is more likely to favour the development of care co-ordination, and, therefore, continuities of care, than co-ordination by care network.*

Some detailed findings that tend, on balance, to support this hypothesis are outlined above. Care co-ordination in the NHS relies heavily on care networks because the tripartite NHS structure (see *Chapter 1*) is a radically fractured form of consultation model. Because of the small scale and scope of general practice services, patients who require round-the-clock or multiple services have immediately to be referred from their general practice to other providers. Care network co-ordinating bodies exist partly as a workaround for this problem. It might, therefore, appear that a single-provider model of primary care would improve care co-ordination, compared with care network structures. 'Single provider' connotes one organisation (not a network) providing primary care medical, nursing and other clinical services (therapies, mental health, pharmacy, diagnostics, etc.). Its internal structures would include interdisciplinary teams based on care groups or care plans, and hence relying heavily on 'matrix', 'organic' or 'project' methods of management,

with highly standardised and (so far as is consistent with patient confidentiality) open information and communication systems. It would depend much less on multiagency networks than do current general practices. That raises the question of who might own and operate such a provider. This study describes the following possibilities:

1. A publicly owned polyclinic on, for instance, the Swedish PHCC model. The corporate general practices and Swedish PHCCs gave further proof of concept (if it were still needed) of the feasibility of mainly salaried general practice in NHS-like settings.
2. A corporate primary care provider.
3. A polyclinic operated by a co-operative, clinician-owned or other 'third-sector' organisation.
4. A professional partnership of larger scale and, above all, scope than is now usual in the NHS.

Any of the above could be managed, and where applicable owned, by doctors, nurses, other clinicians or a mixture. Further options exist.²⁷¹

Our empirical findings also suggest that structure is not everything when it comes to improving care co-ordination.²⁰⁸ Personality (patients' and clinicians'), patients' resources, rurality, organisational size and managerial performance and discretion also have impacts.

Research question 5: implications for managerial practice

We present these implications by domain of practice.

Patient experience

In theory, patients participated in the governance of these organisations and networks, but they and their impacts were not conspicuous. The voice of the patient and carer remains somewhat silent. This 'dog that does not bark' is significant given the rhetoric exhorting agencies to be more attentive to such a voice. The organisations and networks we studied had few other methods for capturing the 'evidence' of patients' experience of continuities (or discontinuities) of care. This dearth has some technical implications: those of ascertaining what aspects of patients' experience are most important to include in outcome frameworks, in particular what combination of standardised and idiographic measures (i.e. of individual care) are required, and how all these measures are to be produced.

We accumulated some evidence about how patients co-ordinate their own care: by becoming well informed about their health problems and willing to question what was being done or proposed for them; by obtaining help from their spouses, informal social networks and friends; and by self-referrals (also to 'alternative' medicine: a bone-setter, for one of our interviewees). Many patients were stoical rather than help seeking. Others easily became discouraged when seeking help. The 'patient choice' model was only partly realistic. Patients often required practical support to use a personal budget, even if they wanted one. The more unwell and vulnerable a patient was, the correspondingly lower their capacity for co-ordinating and managing their own care. The implication is that health-care providers need a better understanding of how patients co-ordinate their own care (a bigger activity than 'managing' one specific condition) and how to provide services that are supportive of and complementary to that activity.

Clinician development

Implications therefore follow for making the training and education of clinicians less single-disease oriented and unidisciplinary, with more emphasis on working across occupational and organisational boundaries and on ways of managing delegation within primary care teams (an issue intermittently discussed since at least 1980²⁷²) in the absence of line-management relationships and some of the frictions, reported above, that the consultation model can generate; that is, promoting a flexible, not only an expert, practitioner identity. That implies altering professional supervision and support to match, in particular enhancing cross-boundary supervision of practice; and selecting clinicians for (besides expertise) personal qualities such as communicativeness and compassion. Our evidence (frequently evidence of its absence) suggests that a care plan, shared among providers and with the patient, is an important means of co-ordinating a

patient's care and strengthening continuity of care. Recording and sharing a care plan requires, however, information systems that capture this (and the supporting clinical) information and allow the relevant professionals shared access to it.

Provider management

For health-care providers, a normative implication is the importance of managers giving continuity of care, and patients' experience of it, a high place in their objectives. That implies promoting informational continuity (with IT implications); the flexible practitioner role; and exercising discretion (e.g. tolerating workarounds) to prevent performance management becoming the enemy of compassion, so that organisational structures do not hamper staff from 'going the extra mile'. Other implications are the necessity of encouraging service colocation and liaison, minimising the sedimentation of duplicate protocols and pathways, and promoting an organisational culture that transcends occupational silos. The shift from 'corner shop' general practice (often single-handed) to larger 'high-street chain' practices has been highly variable across England.

Commissioners' roles

Commissioners, some of whom are GPs, seem ill equipped to deal with this growing agenda. The preceding chapters have illustrated a dearth of the requisite skills among commissioners and, so far, an unwillingness and inability to address the issues of the small scale of general practice. Bar a few experiments, the parties to NHS service agreements and contracts are single-provider organisations, not care networks. These findings would appear to have implications for the roles of H&WBBs and their Joint Strategic Needs Assessments, assuming that these mechanisms will prove powerful enough to have a practical impact on care co-ordination. The normative implication of managers giving continuity of care, and patients' experience of it, a high place in their objectives is also relevant to commissioning. However, we repeat that the new commissioning regime is still young, and during the time of our fieldwork the commissioners' dominant focus was on establishing the new commissioning processes and systems.

Revisions to the initial analytic framework

Our empirical findings necessitated the following revisions to our initial analytic framework.

In the consultation model of care co-ordination, the *captant* professional has two roles, which are becoming gradually more distinct: that of initially responding to changes in the patient's condition and that of co-ordinating his or her care overall. When case management schemes are added to care co-ordination by a primary care doctor, two parallel 'consultation model' structures operate simultaneously, creating additional co-ordination tasks. The production of continuities of care requires not just that care co-ordinators and care plans exist, but that each patient has just one care co-ordinator with overarching responsibility for his or her care, and, correspondingly, one overarching care plan.

The colocation of organisation appears, in practice, to have little practical effect on the linking of formal IT systems, even though it facilitates informal information exchange (informal continuity). Recently integrated organisations also inherit the discrepant information systems of their formerly separate constituent services. In this transitional stage the newly integrated organisation retains this network-like characteristic, and perhaps others. A collaborative culture appears as much to emerge from as to precede interprofessional and interagency collaboration.

Our findings also suggested dependencies between the different kinds of continuity of care. Especially at the interface between health and social care, continuity of access ('flexible' continuity) was a precondition for cross-sectional and longitudinal continuity. Informational continuity was a practical precondition for flexible and cross-sectional continuity. Relational continuity helped to produce flexible and informational continuity. In our view, these relationships merit further research.

Limitations and qualifications to the findings

Our purposive sample of patients was drawn to select patients with specific health problems and hence with recent experience of continuities of care in the relevant services. In addition, the numbers were small, as for practical reasons is usual in qualitative research. Consequently, our sample of patients had little experience of some services (e.g. mental health or out-of-hours services), and thus could report little about the continuities of care experienced with those services. (Some of those who, according to their patient records, had mental health problems did not appear to be getting mental health service support.) If those services used different co-ordination mechanisms from the services that our patient sample had mostly experienced, such co-ordination mechanisms may have been omitted from this study. Some co-ordination mechanisms that we could study, however, did also extend to the under-represented services (e.g. the consultation model, multiagency teams) and these mechanisms tended to be generic and important ones in local health economies overall.

Because of the focus of our RQs, our findings from the sample of patients focus on patients' experiences at the hands of agencies and professionals. We have given less attention to reporting here how patients who co-ordinated their own care did so, or how their efforts interacted with those of agencies and professionals. Patients' accounts of their experiences are inherently subjective. Their accounts could exhibit apparent contradictions, whether borne of tensions between public and private narratives²⁷³ or of nuanced attitudes (e.g. the NHS in general as good vs. their particular experience as poor). We could validate their accounts of their contacts with services, and to some extent of their experiences of care co-ordination, against their medical records. Otherwise, we relied on triangulating patients' accounts against those of other patients and of health workers, and health workers' accounts against those of other health workers and documents. Finally, it bears repeating that the study's aim was qualitative; that is, to identify care co-ordination mechanisms, how they produced continuities and discontinuities of care, and how organisational structures constituted and constrained these mechanisms. Our aim was not to make statistical generalisations (and we did not interview enough patients or health workers for that), but to expose and describe these qualitative relationships, for which we required a rich variety rather than a large number of informants.

Similar methodological reasons informed our selection and the number of study sites. *Table 10* compares certain characteristics of our study general practices, as evidence of how typical the care co-ordination activities and management within them are likely to be of others in England.

TABLE 10 Study general practice characteristics

Study site	GP head count	Practice list	Contract	Teaching practice?	Has GPSI?	QOF score above (+) or below (-) England mean	Ownership
Fivecastles	3	3500	GMS	Y	N	+	Corporate
Eastmere 1	6	9000	GMS	Y	Y	+	Partnership
Eastmere 2	5	4500	GMS	N	N	+	Partnership
Sedgeton 1	5	7500	GMS	Y	N	+	Partnership
Sedgeton 2	6	11,000	GMS	Y	N	+	Partnership
Whinshire 1	8	16,000	GMS	Y	Y	-	Partnership
Whinshire 2	5	10,000	GMS	Y	Y	-	Partnership
Tarrow 1	7	11,000	GMS	Y	N	+	Partnership
Tarrow 2	6	9000	GMS	Y	N	+	Partnership
England mean/mode	4.42 ^a	7041	GMS	N	N	N/A	Partnership

N, no; N/A, not applicable; Y, yes.

^a September 2011 data. Sources: NHS Information Centre, Public Health England 2013: <http://fingertips.phe.org.uk/PROFILE/GENERAL-PRACTICE>. List sizes rounded to nearest 500 for anonymisation.

The high level of use and the diversity of general practice IT systems are known to be typical of the NHS generally. Our study general practices either kept frequent contact with CCG leads or had them as partners, and hence perhaps were more likely than other general practices in practical terms to support initiatives to set up care networks and enhance care co-ordination in other ways. They were slightly larger than average and more likely to be training practices and so perhaps more attuned than most general practices to current policy and knowledge of good practice regarding care co-ordination. If so, this study may err towards overestimating the extent and variety of care co-ordination mechanisms in general practice. In our study sites, as across the UK, only a minority of practices had GPSIs. Notwithstanding the different contract types, the payment criteria and basic contractual requirements are essentially similar for all general practices in England. Apart from one being corporately owned (and chosen as a study site for that reason), these general practices otherwise appear, in the respects shown in *Table 10*, to be fairly typical of most others in England.

A final empirical limitation is our choice of Sweden as a source of examples of integrated, publicly owned primary care providers. Because many other examples exist elsewhere, our conclusions will err towards conservatism in considering the range of organisational possibilities for such providers.

Further research

This study was methodologically unusual in applying an 'inside-out' method of analysis, working forensically from patient experiences 'outwards' or 'upwards' to the organisational structures (and other factors) that produced them, and then outwards to the care network factors that produced or constrained care co-ordination at an organisational level, and then outwards again to the health-system level. Patient experiences did indeed identify problems (and successes) in maintaining continuity of care that required explanation, but health workers identified more. Health workers see many patients and see the underlying 'iceberg' of organisational practice and co-ordination mechanisms, which are partly behind-the-scenes as far as patients are concerned. Nevertheless, this study does provide proof of concept that a qualitative variant of this analytic method is at least practicable and, in our view, has produced some explanations about how and why care co-ordination occurred, or failed to. The method, therefore, appears worthy of further effort to refine and develop it.

Our application of this method also identified questions requiring further research. We list them in what, in our opinion, is descending order of practical importance.

1. How alternative ways of co-ordinating post-discharge care across the triple interface (hospital–general practice; hospital–CHS; CHS–general practice) compare in terms of their impacts on continuities of care.
2. What effects increasing the scale and scope of general practices has on continuities of care, comparing in this respect partnerships, corporate general practices and large federations (i.e. networks) of general practices.
3. What effects on continuities of care result from alternative approaches to information system design (e.g. open standards versus proprietary turnkey projects), information governance (regulations about confidentiality, data ownership) and the design of health records.
4. How patients co-ordinate their own care (a wider question than how they go about self-management of a single condition, or help seeking) and when and how to provide services that support patients' co-ordination of their own care and are complementary to it.
5. Whether or not the assumptions that there are economies of scale in centralising CHS at locality level, and that the benefits of doing so outweigh the informational, flexible and relational continuity advantages of collocating them at general practices, are valid.
6. At what scale(s) the balance of advantage shifts from widening the range of general practice services by network means (collocation, subcontracting) in favour of widening it by adding services or departments to an integrated organisation.

7. What methods and measures, including idiographic measures, are required for capturing the 'evidence' of patients' experience of continuities (or discontinuities) of care for the purposes of service delivery and development.
8. How the consultation model of co-ordination interacts with a care pathway model of care co-ordination, in the context of specific care pathways, and with what effects on continuities of care.
9. QOF appears to be a driver (as expected) of care co-ordination, but it remains unclear what other incentives might stimulate more or better co-ordination of care, given the tripartite organisational separation of general practice, CHS and social care.

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Contributions of authors

Rod Sheaff (Professor, Health Services Research) designed the research, conducted the organisational analyses, contributed to fieldwork in England and Sweden, synthesised the results and prepared them for publication.

Joyce Halliday (Associate Professor, Social Policy and Sociology) conducted the research into patient experiences, and led the organisational fieldwork in England, contributed to it in Sweden, and contributed to synthesising the results and preparing them for publication.

John Øvretveit (Professor of Health Improvement, Implementation and Evaluation) contributed to the research design, conducted the Swedish research and contributed to analysing the results and preparing them for publication.

Richard Byng (Professor, Primary Care Mental Health) contributed to the research design, case study analysis and preparing the results for publication.

Mark Exworthy (Professor, Health Policy and Management) contributed to the research design, English case study fieldwork and analysis and preparing the results for publication.

Stephen Peckham (Professor of Health Policy) contributed to the research design, links with London polysystems evaluation and synthesising the results.

Sheena Asthana (Professor of Health Policy) contributed to the research design and synthesising the results.

Data sharing statement

Data used in this study can be obtained for the purpose of openly-published scientific research from the corresponding author, but to conform with the ethical approval for this study it can only be supplied in an anonymised form.

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Appendix 1 Care co-ordination by the patient

Although patients are often viewed as passive, most expect to, and can, have a role in co-ordinating their own care,⁹⁰ and when health professions fail to co-ordinate care, they sometimes have to do so.⁵ Care co-ordination by the patient himself or herself depends on the patient using his or her own resources to self-refer to services directly, or on the patient's success in persuading a gatekeeper to make the referral. It is an important component of patients' self-management of their health. Patients who co-ordinate their own care usually combine free services, paid care and unpaid care, and nuanced ways of calling on complex informal networks of relatives and friends.^{120,121}

The severity of the condition and the level of distress have been found to be strong predictors of help-seeking for mental health problems.¹²⁸ The inverse care law appears to be less applicable in ED services (mostly accessed by self-referral) than in, say, mental health services (mostly accessed by GP referral).²⁷⁴ For more dependent older patients, care transitions (often, into a nursing home) may be effected by their informal carer, especially when the carer's skills are ill matched to the patient's needs. A US study found that male informal carers (especially husbands and sons) were more likely to transfer care than were female carers, as were informal carers of the opposite sex to the patient.¹²⁶ Patients who believe that they can 'manage by themselves' are less likely to disclose their problems to the GP.^{122,124} Nevertheless, formal services can also help patients self-manage: for instance, for psychiatric problems they may include such factors as helping to manage their financial affairs.¹²²

The burden that the task places on patients and their carers is one limit to patients' self-co-ordination of care. There appear to be limits to how far patients are usually willing to travel to receive secondary care,¹²⁴ a factor that may especially apply to older people with limited mobility and who often rely on public transport. Caregiver burden appears to be a predictor of the institutionalisation of frail older people, especially those with dementia.¹²⁵ It appears reasonable to assume, although there is little corroborating evidence, that a patient's enduring contact with a single provider leads to stronger relationships, better information transfer and more consistent management.⁸² Cross-sectional, longitudinal and relational continuity of care are likely to break down when users are highly mobile even within a small locality, for instance for patients with serious mental illnesses.^{130,131}

For mental health care, seeking help from formal services depends also on how the patient perceives his or her likely reception. Patients' perceptions of a GP's competence, openness, social distance (lower socioeconomic status patients perceive GPs to be higher in socioeconomic status and therefore to lack an understanding of poverty) as well as trust in the GP influence the extent to which a patient is willing to disclose his or her problem.¹²⁸ Fear of rejection, shame and embarrassment are emotional barriers to psychological treatment.^{131,275} Patients' expectancies of treatment have also been found to affect help-seeking;²⁷⁶ for example, patients may believe that all the GP will do is prescribe antidepressants. Among people with depression, women perceive more barriers than men do to accessing help.²⁷⁷

However, unless the patient is able to pay privately (and the provider is willing to accept such work), access to many services is by referral only. Then the patient has to persuade a gatekeeper (typically a GP or social worker) to make the referrals that he or she wants. An individual professional or manager might collude with the patient in supplementing official with unofficial resources – that is, the patient's or informal carer's own preferences and resources, such as transport²⁰⁵ – when deciding where to refer a patient. Two studies^{121,278} of patients' and clinicians' views on the aims and benefits of care co-ordination note that these sometimes differ, although a third (small) study of acute care¹⁰⁷ suggests the opposite.

As far as mental health services are concerned, GP referral decisions depend, *inter alia*, on the patient's initiative in requesting or showing interest in referral to mental health services.²⁷⁹ Patient intelligence and ability to articulate problems are related to psychological mindedness, which has been found to predict benefit from therapy.²⁸⁰ Factors involved in GPs' referral decision included the GP's estimate of the

patient's capacity to benefit from psychological therapy, and that of the GP's own capacity to help the patient in terms of skill, expertise and time.²⁷⁹ GPs' decisions were affected by patients' help-seeking behaviour and their representations of mental health problems; the ability of the GP to detect the disorder; GPs' attitudes towards psychological problems and their management; service criteria for appropriate referral; and links with other mental health services.²⁸¹ Patient factors that may affect access include the level of knowledge of the individual; the relationship with the GP; emotional barriers; self-reliance; and the perception of benefits. People often do not know where to get help for emotional problems and have little awareness of available treatments.^{118,282,283} GPs' perception that they had reached the limit of their capacity for treating patients with mental health problems, the patient's suitability for therapy and access to psychological therapy services were further key factors influencing GPs' referral decisions.²¹⁷

Appendix 2 Diverse organisational ownership: some implications for care networks

To patients' transitions between professional silos, a care network adds transitions across organisational boundaries. (Transitions between primary and secondary care remain in any event.) Care networks' co-ordination structures are added to those that exist within each member organisation. If we grant this assumption temporarily, the question then arises as to what sort of integrated organisation is preferable from the standpoint of care co-ordination. Current NHS policy aims to recruit increasingly diverse types of care provider. The main organisational types currently found in the NHS (and their corresponding organisational aims) are:

1. corporations (pursuing return to investors)
2. professional partnerships (personal income, professional interests)²⁵⁶
3. owner-managed small firms (personal income, asset value)
4. social enterprises (normative and local aims)²⁸⁴
5. producer co-operatives (personal income, economic security, control over work)
6. voluntary organisations (normative aims)²⁸⁵
7. public firms (policy implementation)
8. hybrids of the above.²⁸⁶

Having different owners, objectives and internal managerial regimes,^{38,287,288} these different types of organisation might be expected to differ in how they interpret and implement care integration and what priority they give to it. That is, how far are the care processes that different kinds of provider organisation select, in pursuit of their multiple and diverse objectives, compatible with the requirements for care co-ordination and continuity outlined in *Chapter 2* (coherence of rules and policies at different organisational levels⁸⁶)?

For example, social care networks in England, France and Germany appear spontaneously to separate profit from non-profit services.¹⁸⁶ (The situation is similar among commissioners; and US commercial insurers are more likely than Medicaid to promote managed care.²⁸⁹) In social care, low wages leading to high staff turnover are an obstacle to maintaining relational continuity of care.¹⁰⁹ A small qualitative study²⁹⁰ in Ontario suggested that when the substitution of community for hospital care occurred in a context of the introduction of quasi-markets for social care, more precarious employment conditions for home-care workers and inconsistent care providers, a 'degradation' of the quality of home care for older women resulted. In France, some social care co-ordination centres are cofinanced with banks and insurance companies 'looking for cross-selling opportunities'.¹⁸⁶ Evidence on these questions is sparse, mostly indirect and equivocal.^{291,292} Providers owned by organisations that also pay for health care (e.g. Veterans Administration, Kaiser Permanente, Group Health and the NHS) appear to give care co-ordination a higher priority. Narrowly focused providers often lack incentives and structures to do this, as may those charitable providers concerned only with a closely defined care group.

Appendix 3 Case study site vignettes

Site 1: Eastmere

Eastmere is a large, very rural county with some areas that have consistently high levels of deprivation. Its population of circa half a million people is predominantly white and older than average. The county's dispersed nature poses challenges for service delivery and accessibility, making the ability to deliver services closer to home of particular interest.

Eastmere was chosen as representative of the tripartite model, the normal structure for health and social care delivery in England. Health and social care in Eastmere has, until relatively recently, been the subject of considerable geographical disaggregation. Two-tier local government prevailed until 2009, when a countywide unitary authority was created. Health was similarly disaggregated (following the district council boundaries before a process of gradual consolidation). There is now a countywide Care Commissioning Group divided into 10 GP localities.

A countywide community interest company provides adult CHS (including district nurses and community matrons). Its website suggests that it is seeking closer integration with social care, better grass-roots relationships and a reduction in repetition/inadequacies of patient information transfer. Services for mental health and learning difficulties are similarly provided by a (separate) single countywide trust. The trust includes two hospital units that support people with dementia, a memory service and a complex care and dementia liaison service, providing countywide support to a number of dementia registered care homes and community hospitals. In contrast, acute care is provided by three acute trusts, only one of which lies within the county.

The two general practices we studied were located within the same GP locality in the east of the county and looked towards a neighbouring administrative unit for acute care. One was of above-average list size for England (circa 8500) and was a training practice, whereas the other of below-average size (circa 4500), and had a high proportion of patients with long-standing conditions. Both scored highly in terms of QOF points and patient satisfaction. The GP locality has three community hospitals based in small towns.

The health and social care economy has been the subject of a series of recent initiatives focusing on preventative services and partnership working, including patients with long-term conditions and complex and multiple needs (particularly the need to address the growth in repeated unplanned admissions). This resulted, for example, in the introduction of rapid access teams, community matrons and an acute care at home service.

More recently, this imperative has been given a locality focus with the creation of provider-led health and social care hubs. These are based on the old district council/social care team boundaries and were piloted in our study area. The model is based on a team of health and social care workers (with separate employing organisations). The aim was to act as a single-number co-ordination centre, providing a point of central access and triage for referrals and directing patients onwards to the most appropriate team. The intention was to integrate short-term (enablement) support, therapy, community nursing, the hospital discharge teams from both acute and community hospitals, mental health nursing and intermediate care, with referrals from GP practices. The independent sector, voluntary and community sector, hospitals and ambulance service are also to be able to refer directly.

A MDT met originally on a weekly basis to look at referrals, and discuss the most appropriate action and the best person to deal with it. A second key feature was the development of personalised support plans to which the whole team has access, but which have clinical and client ownership. The requirement for a case management information system was identified early on, as was the need to pool sundry budgets. Organisational sign-up and staff commitment have, however, been variable and resources have been constrained.

Site 2: Whinshire

The county of Whinshire is a relatively wealthy area with low deprivation. It was the largest of the five study areas in population terms and is among the fastest-growing counties in England. It was also the most ethnically diverse and youngest of our counties (excluding the conurbation). The practices we studied in particular (which were urban and suburban in location) served significant Asian and 'white other' groups.

Whinshire was chosen because it had a large, intensively managed care network involving nearly all the general practices in the county, the out-of-hours primary care service, the combined community health and mental health trust, the two acute trusts that serve the county, social services, the ambulance service and third-sector partners across the county. The aim was to develop new models of long-term condition management in order to help patients remain independent for longer and have more choice in their end-of-life care. Specific objectives included a community elderly care service to assess and support elderly, frail patients in remaining independent and the introduction of personalised care plans for high-risk individuals.

The county had an integrated community and mental health services trust. Otherwise, provider organisations have continued to remain distinct. The lead organisation is now one of two CCGs covering Whinshire (commissioning services for the largest portion of the county's population). Its component practices have been divided into eight localities, with our sample GP practices falling into two of these localities. It was also the only county studied where the sample population fed two separate acute trusts operating in close proximity. Like Fivecastles, the county still has two-tier local government, with one county council and six district or borough councils; the two practices we studied fell into different districts. These practices were both larger than average training practices (one had more than twice the average patient list for England). They were ethnically quite diverse, with respondents noting high proportions of first-generation Eastern European migrants. These practices were the only ones in our study to have lower QOF scores than the national average.

Whinshire already had a 'proactive' care model in place before the inception of the Integrated Care Project. This was GP practice based and essentially involved, as the name suggests, proactive case finding and holistic assessment of patients who are vulnerable and at risk of admission by a named GP and a community ANP. They produced both a goal-centred care plan (focusing on long-term condition management) and an anticipatory care plan and they met weekly to review cases. Administrative support was given to the GP practices to ensure that information was fed back to the commissioners. A proposed frail and elderly care pathway would extend the model to include community MDTs while continuing to focus on practice-based meetings.

The second element of the frail and elderly care pathway was an intermediate care team for both crisis response (admission avoidance) and facilitated discharge. It was equally funded by health and social services, and encompassed social and physical (nursing and therapy) rehabilitation, mental health care and access to long-term social care in clients' homes or access to care homes. It also included a presence in both EDs and selected hospital wards, diverting admissions and facilitating discharge. It was supplemented by a crisis hub that provided single point of referral with one telephone number, triaged by senior health and social care professionals at the point of referral.

Site 3: Sedgeton

Sedgeton was part of a larger conurbation with a total population of circa 300,000. This was the most ethnically diverse of our study areas (albeit only a little more diverse than the national average) and had a younger than average age structure, with circa 13% of the population aged 65 years or over, compared with over 21% in study areas 1 and 4 (the national average is 16.3%). Using the Index of Multiple

Deprivation 2010²⁹³ ranking of average ranks, it was also the most deprived of our study areas, although (reflecting a bias in our selection, which was motivated by organisational form) it still fell just outside the worst third of local authority areas nationally.

Sedgeton was selected as a study site for its virtual 'polyclinic' housing networked colocated services. The conurbation was served by separate (non-coterminous) acute, community and mental health trusts. The CHS trust covers the conurbation together with one of the two adjacent counties. The acute trust covers the conurbation and parts of two adjacent counties, providing tertiary and specialised services to a larger catchment area. The mental health trust covers the conurbation and the whole of the two adjacent counties, with again a wider reach for tertiary services. The conurbation itself is a unitary authority for local government purposes and the CCG and city council boundaries are coterminous.

All three NHS trusts as well as the city council's housing office have clinics or offices in the 'polyclinic' that we studied. The acute trust offers a range of outpatient clinics on a weekday basis, including pain management, cardiology, respiratory medicine, neurology and orthopaedics. It also operates a minor theatre and recovery, where patients receive injections for pain. The mental health trust offers psychological services, psychotherapy and behavioural therapy, with an inpatient facility operating from an adjacent site. The community trust offers, for example, foot health, hearing tests, phlebotomy, speech and language, and community nursing.

This was not a classical polyclinic model in that there were no colocated GP services. Instead, a group of practices refer into the other services at the 'polyclinic'. Our starting point was two professional partnership GP practices that did so (although only one was actually part of this cluster or locality). One was of average size; the other was the largest in our study, with a list size of over 11,000. Both were training practices with above-average QOF points but they varied in, for example, ethnic diversity, age of population, proportion of patients with a long-standing condition and patient satisfaction.

Long-term community services (excluding specialist nursing teams) had relatively recently been reorganised to create IPCTs. These serve clusters of GP practices (although none is colocated), with the studied 'polyclinic' forming the centre of one such cluster. The IPCTs are multidisciplinary, including ANPs, nurses, physiotherapists and OTs. The planned links to social care and mental health on a locality basis are more tenuous. However, the IPCT serving the 'polyclinic' included a seconded social worker and carer support worker. The IPCTs have regular MDT meetings and also meet with GP practices on a monthly basis, expanding the scope of their pre-existing gold-standard framework (palliative) meetings to consider complex house-bound patients. One of the practices we studied, for example, had made attendance at this meeting mandatory for all its GPs and attendees here were not just the ANP but the district nurse, the physiotherapist and the OT.

A federation of GPs, of which the practices we studied were a part, also secured support from the Prime Minister's Challenge Fund towards the end of the study period. This will involve the practices working in partnership with one another as well as the voluntary sector and local pharmacists to provide a more responsive service, including care navigators to support independent living, with a particular focus on older people.

Site 4: Tarrow

The county of Tarrow, with a population of fewer than 200,000, was by far the smallest of the localities we studied. This, combined with its rural nature, a dispersed population and high levels of older people, posed many challenges for the delivery of health and social care. For example, the catchment population of the county and surrounding areas was half of what is now considered necessary nationally to support a fully functioning DGH with A&E, maternity, intensive care, medical and surgical specialities. However, its geographical position and distance to other cities meant that considerable weight is attached to both a

local, centrally situated hospital with a broad range of specialities and to strong locality- and community-based services. Predicted growth was confined to the over-65 client group, the largest consumer of services.

NHS Tarrow had for some years already shared a single chief executive and management team with the coterminous unitary local authority and had established joint local authority/PCT commissioning for health care. At the start of our study period, Tarrow provided integrated acute, adult CHS and social services (the latter paid for under a '§75' pooled funding agreement). Elements of the local health and social care system remaining outside the new organisation included general practice and primary care, children's services, mental health services and the ambulance service (as well as the private health sector and the third sector of community, voluntary and charitable associations). There was also a single countywide CCG, which held pathfinder status. Mental health services were provided by a separate trust serving both Tarrow and a neighbouring county.

Service delivery was based on a locality model rather than around GP practices. Locality teams were planned to comprise GPs, social care professionals, nurses, therapists and support workers, responsible for the overall care of service users and with responsibility for delivering services, using a case management/care co-ordination model. This was to include rapid response/instant care, intensive home support (up to 6-week duration) and domiciliary rehabilitation and recovery. Implementation was not smooth, however, and during the course of the study adult social care services returned to the direct control of the local authority, a joint acute and CHS trust.

The two practices we studied lay in different parts of the county: one city based, one market town based. Both were larger than average training practices with high QOF points and average/above-average levels of patient satisfaction. One had the highest proportion of older people found in our study (1.5 times the national average).

Towards the end of the study period, Tarrow piloted two distinct virtual ward schemes: one consultant-led with the aim of facilitating discharges, the other GP-led with the aim of preventing avoidable admissions. The latter was multidisciplinary, including community matrons, nurses, physiotherapists, OTs and health-care assistants, and also interorganisational by virtue of both a central role for GPs and the inclusion of social care staff as partners. Elements included MDT meetings in the GP surgery to identify/allocate patients, allocation of a key worker, goal-driven care plans and a daily virtual ward round. The older persons' community mental health team also had a multidisciplinary/interorganisational element, including seconded social workers and social care staff as well as nurses and nursing assistants and an OT, with referrals triaged and allocated at a weekly MDT meeting.

Site 5: Fivecastles

The county of Fivecastles has a population of circa 500,000. Although a significant proportion of its population lives in rural areas, it has an essentially suburban character and is best described as an affluent home counties commuter area. It ranks highly in terms of not just gross domestic product per capita but also quality of life, life expectancy and education. Proximity to a major city means that it supports a more ethnically diverse and younger population than many of our study areas.

The focus of the case study was a corporate GP practice that was part of a primary care company providing community-based health care for the NHS. The parent company operates a number of GP surgeries and GP-led health centres in the UK on behalf of health-care commissioners, providing practice management/operational and management structures. GPs have an employment contract with the parent company and staff have their employment contracts transferred under the TUPE [Transfer of Undertakings (Protection of Employment)] Regulations. They are provided with access to an infrastructure that includes clinical governance support, prescribing support, practice-based commissioning support and administrative support for areas such as QOF. The company also provides community-based outpatient clinics through

its community clinical assessment and treatment services, focusing on primary care ophthalmology, sexual health and ear, nose and throat. A stated aim is to bring appropriate clinical services out of hospital and into the community so that patients can be treated closer to home, and the company's ethos reportedly supports referrals to other private/designated providers (e.g. diagnostics and pharmacies). At the time of the study it also had an interest in delivering in-reach services to community hospitals and nursing/residential homes.

The relatively restricted commercial base of the parent company meant that the practice studied was also embedded in the wider health and social care economy. An integrated NHS trust provided both acute and community services for the majority of the county. During the study period, acute services retrenched to focus on just one site, ED facilities at a second site being reduced to a GP-led minor injuries and illness centre. The trust also provided services from a number of community hospitals across the county. Mental health services were provided by a separate trust that, as with study area 1, covered this and an adjacent county. With the exception of one unitary authority, this remained a two-tier authority administered by a county council and four districts.

There are two CCGs and seven GP/community health localities. Our studied corporate practice is one of nine in its locality, and is served by a community hospital that until relatively recently also provided acute care. It is a training practice and the smallest in our sample, with a list size approximately half the national average. It had a very high QOF score, with levels of outpatient and ED attendance well below the national average. However, levels of patient satisfaction were also below the national average.

The county council has been active in seeking alignment with the health economy, one result of which was a programme director for integrated health and social care based within the council. It has also employed an independent consultant to address issues of integration and alignment. One product has been the development of a variant on a virtual ward model, led by the council working with the CCG. These multiagency groups have been rolled out across the county, and involve a core group of professionals comprising a GP, a practice nurse, an adult and community health team, mental health, a social worker, a community practice worker and a care co-ordinator (who facilitates the meeting). The individual 'wards' meet fortnightly in GP practices to discuss a small group (maximum eight) of at-risk patients, each of whom has a key worker and is subject to regular review. The community practice workers attending these meetings are part of another key local development (led by the county council but funded by the health sector and delivered in partnership with the voluntary sector), which focuses on preventative support for adults who are at risk of needing more intense social care or health services in the near future.

Appendix 4 Specimen interview schedule: health workers

Universities of Plymouth, London and Birmingham, and Karolinska Institutet Stockholm.

Integration and continuity in primary care: polyclinics and alternatives.

Interview schedule: health professional

Instructions to interviewers are in *italics*.

Before starting interview:

- *Check interviewee has seen the Participant Information Sheet.*
- *Invite interviewee to ask any questions about the research and what is expected of him/her.*
- *Ask interviewee to sign consent form (two copies: one for interviewee, one for researchers).*
- *Ask permission to audio-record.*
- *Offer interviewee opportunity to see and correct transcript.*

Checklist of topics

Interviewer to select ad hoc which of these to pursue with particular individual informants, according to what appears relevant to the informant's role, the nature of the particular study organisation and what data are already available to the researchers.

Tracer: services for frail elderly people, including unplanned hospital admissions for elderly people with complex chronic health problems.

Patient [name of index patient] is a patient on our study. Thank you for familiarising yourself with his/her care before the interview.

- How would you describe the overall co-ordination of her/his care?
- What works well/less well? Why?
- Who is involved? How do they work together?
- How do record systems help or hinder coordination?
- How could organisations work together better?

Care coordination within-organisation for frail elderly patients with complex chronic health problems:

- How is care shared between the different professionals in this team?
- Who makes decisions?
- How are records kept? Who uses them?
- How is care shared between different teams in the organisation?
- Does it rely on transfers of responsibility or distributed/shared responsibility?
- Within this organisation, what organisational factors facilitate or inhibit coordination of care for frail elderly patients?

Case management

For frail elderly patients with complex chronic health problems:

- Who coordinates their care? [Case Manager? GP? Someone else (who?)?]
- Are there designated case managers? What is their role?
- Or is there an informal system of case management?
- For such a patient, how often does the case manager change?
- Why does the case manager change?
- Do patients have written care plans? (Could we see an anonymised example or a blank pro-forma?)
How are these integrated with the records?
- When do case-managed patients have their needs reviewed?
 - Periodically?
 - With formal risk management?
 - In response to health events?

[PROMPTS]

1. exacerbation
2. progress of disease
3. new health problem
4. major life event (e.g. loss of spouse or other carer)?
 - At patient's request?
 - At clinician's discretion?
 - On other occasions? (Which?)

External referral

- What are the main transfers or referrals to external organisations or other sources of care?
 - Are any of these colocated with you (i.e. based in the same clinic or workplace but employed by different organisations?)
 - *IF YES:* what are the practical benefits/disbenefits of colocation?
- What factors help in ensuring that patients referred to these organisations receive prompt service?
- Do you face any incentives – or disincentives – to refer to particular services? What are these dis/incentives?
- What are the main causes of any delays or restrictions to the referred patient(s) actually receiving the service?
- Are any services only available externally, although it would be possible to provide them 'in-house'?
- Are there any services to which you would like to be able to refer frail elderly patients with complex chronic health problems, but cannot?
 - *IF SO:* why can you not make these referrals?

[PROMPTS] Because these services are:

1. Not available locally (at all, or enough)?
 2. Available, but not budgeted/contracted for ('rationed')?
 3. Administrative preconditions (authorisations, documentation, etc.)?
 4. Evidence-based medicine-based limitations?
- Are there any other problems with using external services?

[PROMPTS]

1. Transfer of records and data between workers and organisations?
 2. Access to information about what care the patient received?
 3. Non-organisational factors (e.g. practitioners' local knowledge, personal skills)?
- Specifically, are there any problems with [service(s) reported as problematic by documents or patient informants]?

Other aspects

Finally, is there any other important aspect of the integration and continuity of the primary care services in [organisation name] which we have not yet asked about?

Appendix 5 Interview schedule: patients

Universities of Plymouth, London and Karolinska Institutet Stockholm.

Integration and continuity in primary care: polyclinics and alternatives

Interview schedule: patient

Instructions to interviewer are in *italics*.

Before starting interview:

- *Check interviewee has seen the Participant Information Sheet.*
- *Invite interviewee to ask any questions about the research and what is expected of him/her.*
- *Ask interviewee to sign consent form (two copies: one for interviewee, one for researchers).*
- *Ask permission to audio-record.*
- *Offer interviewee opportunity to see and correct transcript.*

Checklist of topics

Interviewer to select ad hoc which of these to pursue with particular individual informants, according to what appears relevant to the informant's role, the nature of the particular study organisation and what data are already available to the researchers.

Your health

We are interested in your recent experience of healthcare locally, particularly how the different people and organisations responsible for your care work together.

I'd like to start by asking you a few questions about your health in the last 12 months.

1. Can you tell me what health problems and/or disabilities you have at the moment, or in the last 12 months?

[Prompt Card 1] Enter on Table

1. Have there been any major changes in your health/personal circumstances (e.g. loss of spouse or other carer) in this time?

Thinking about everyday activities:

1. Have you had any difficulties in the last 12 months doing any of these because of your health?

[Prompt Card 2]

	On own: with difficulty	With help from someone else	Unable to
Bathing or showering			
Dressing (including putting on shoes and socks)			
Cooking or eating			
Managing medications			
Making telephone calls			
Driving			
Walking outside your home			

1. Do you have any support from social services/care agency etc. because of your health/to help you cope at home?
2. Over the past 12 months how would you say your health has been...?

Excellent/Very Good/Okay/Not so good/Poor

Your health care

1. Can you talk me through how your health has been over the last 12 months?

Use Table to record health episodes. Chart how the episode started (e.g. patient contacted GP), who they saw, where they saw them, who they were referred onto and how this overlapped with other health problems and interventions. (Cards 3–5 contain codes.)

As a result of discussion note:

Whether this resulted in any changes to their care or treatment

Enter on Table

1. Have there been any treatments, after-care/follow-ups that you thought you should have received/would like to receive but haven't? YES/NO

IF 'YES': enter unmet need details on Table

1. How important is it for the health service to find out how you are after any change in treatment or hospital care?

Very important/Important/Not very important/Not important at all.

IF care over the last year includes time as hospital inpatient/outpatient.

- i. How far do you agree with the following statement?

After treatment in hospital, a health professional has always checked all is well once I am back home

Strongly Agree/Agree/Disagree/Strongly Disagree.

1. Are you satisfied with the care you received in the last 12 months? YES/NO.

Ask what aspects of care have produced satisfaction/dissatisfaction.

Record on Table

1. Overall, do you find it easy to see someone about your health care? YES/NO.

Discuss why:

[Free text].

Organisation of health care: care manager

1. Do you think it is important that you have someone who is responsible for co-ordinating your care?
2. Who do you think has the best overview of your care at the moment?

- i. *PROMPT:* do you have a designated care manager/is more than one person responsible/what about the quality of this relationship?
- ii. Has this person changed in the last six months? YES/NO
- iii. *IF YES:* why was that?
- iv. [Free text].

3. How important do you think it is that your medical team appears interested in your health, explains treatment clearly and is open to discussion?

Very important/Important/Not very important/Not important at all

1. Can I ask you how far you agree with the following statements?

- i. My doctor/care manager always has time for me and treats me as an individual.

Strongly Agree/Agree/Disagree/Strongly Disagree.

- i. It is very important to me that I see my regular doctor/care manager.

Strongly Agree/Agree/Disagree/Strongly Disagree.

Care plan/team working

1. Are you aware of a plan for your care?

- i. *IF YES:* have you seen it or contributed to it?

2. What happens in practice: is anything written down? Where is it kept?

3. Can I ask you how far do you agree with the following statements?

- i. It is important that the people looking after me have a shared plan for my care and treatment.

Strongly Agree/Agree/Disagree/Strongly Disagree.

- i. The people looking after me work well as a team.

Strongly Agree/Agree/Disagree/Strongly Disagree.

1. Can you tell me about any situations or events where you got the feeling a professional really knew what other professionals had done to help you or were doing now?

- i. What about any situations/events where you got the feeling a professional did not know what other professionals had done?

Case review/adjustment of resources

1. How important is it that your health care is the subject of regular review and monitoring?

Very important/Important/Not very important/Not important at all.

1. How often is your condition reviewed [as opposed to responding to changes]? Who conducts the review?

[Free text]

1. Do you discuss what is most important to you in managing your health?

Transfer of information

Can I ask you how far you agree with the following statement?

1. The people looking after me always have the information they need to provide appropriate care.

Strongly Agree/Agree/Disagree/Strongly Disagree.

If in receipt of a care package:

1. What about communication with social services?
2. Do they know what health care you are receiving/what do they need to know?
3. And what about with you? How would you describe the amount of information you receive to help you manage your health?
4. Can I ask you how far you agree with the following statement?

- i. I have a clear idea about who is involved in my care and where I should go for more information.

Strongly Agree/Agree/Disagree/Strongly Disagree.

1. Do you know how your records are kept?

- i. Can you add information? Who can add information?

[Free text].

Patient involvement

1. How much have you participated in deciding how you are looked after?

- i. Are you involved as much as you want to be in decisions about your care and treatment?
- ii. What information about you do you hold/think you should hold about your care/treatment?
- iii. Do you feel sufficiently supported to manage your own care?

Absence of interruptions or gaps.

1. Have there been any interruptions or gaps in your care? For instance, any waits, delays, bottlenecks or other interruptions?

[Free text]

- i. *IF YES*: what do you think caused them?

PROMPT: aware of reasons?

[Free text]

1. Overall, what do you think works best about how all the services communicate about your care or co-ordinate their work to help you?
2. Do you think your care could be better organised?

- i. *IF YES*: in what way?

[Free text].

Finally.

1. Is there any other important aspect of your healthcare over the last 12 months which we have not yet asked about?

[Free text]

1. What did you do before you retired?
2. Does your family live nearby/help out?
3. Do you live alone/care for anybody else?

Prompt card 1: list of health issues

Muscular skeletal	Joint/back/pain/arthritis/other
Cardiovascular	Heart problems/heart attack/arrhythmia/hypertension (high blood pressure)/DVT (deep-vein thrombosis)/PE (pulmonary embolism)/other
Lung/chest	Asthma/chronic bronchitis/emphysema/chronic obstructed pulmonary disorder/other
Neurological	Stroke/headaches/epilepsy/fits/other
Mental health	Depression/anxiety/dementia/Alzheimer's disease/panic attacks/psychosis/schizophrenia/bipolar disorder/personality disorder/other
Physical disability/limitation	Limited mobility/falls/diabetes/renal disease or failure/other
Sensory	Blind/deaf/other
Skin/rash	Psoriasis/eczema/other
Alcohol misuse	
Problems under investigation	
Miscellaneous (please specify below)	Cancer/gastro/infections/learning disability/others

Prompt card 2: daily living

1. Bathing or showering.
2. Dressing (including putting on shoes and socks).
3. Cooking and eating.
4. Managing medications.
5. Making telephone calls.
6. Driving.
7. Walking outside your home.

Prompt card 3: how is treatment initiated?

1. Patient.
2. Family member, friend or neighbour.
3. GP.
4. Out-of-hours medical service.
5. Ambulance.
6. Hospital: emergency admission.
7. Hospital: elective admission.
8. Social worker.
9. Other (who?).

Prompt card 4: which professionals did you see?

1. GP.
2. Practice nurse.
3. Community nurse.
4. Community mental health worker.
5. Physiotherapist.
6. Occupational therapist.
7. Speech therapist.
8. Podiatrist.
9. Dentist.
10. Optician.
11. Ambulance crew.
12. Chemist.
13. 'Alternative' therapist or practitioner.
14. Social worker.
15. Home help/carer.
16. Voluntary sector (e.g. support group).
17. Other (e.g. nutritionist, counsellor?).

Prompt card 5: where did you receive health care?

1. At home.
2. At GP (or equivalent) clinic.
3. At another primary care clinic.
4. A&E.
5. Outpatient at hospital.
6. Inpatient at hospital.
7. Community hospital, nursing home or similar (intermediate care).
8. Residential care.
9. Other place(s) (where?).

Health overview: last 12 months

	May (name month 1)	June	July	August	September	October (continue to month 12)
Health problem	Overall: chart patient's timeline (e.g. really ill end last summer)					
	Chart incidence of each health problem against time period					
	Chart how problem started (card 3), who seen (card 4)/number of times seen (e.g. saw GP 4 times June/August)					
	Chart connections (e.g. then referred to district nurse)					
	Chart location (card 5)					
Diabetes		1	GP (X4) surgery	DN (X3) home		

A decorative graphic consisting of numerous thin, parallel green lines that curve from the left side of the page towards the right, creating a sense of movement and depth.

EME
HS&DR
HTA
PGfAR
PHR

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