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Integration and Continuity of Primary Care: Polyclinics and Alternatives, a Patient-Centred Analysis of How Organisation Constrains Care Coordination

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Abstract

Background

An ageing population, increasingly specialised of clinical services and diverse healthcare provider ownership make the coordination and continuity of complex care increasingly problematic. The way in which the provision of complex healthcare is coordinated produces – or fails to – six forms of continuity of care (cross-sectional, longitudinal, flexible, access, informational, relational). Care coordination is accomplished by a combination of activities by: patients themselves; provider organisations; care networks coordinating the separate provider organisations; and overall health system governance. This research examines how far organisational integration might promote care coordination 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 coordination 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.
5. The implications of the above for managerial practice in primary care.

Methods

Multiple-methods design combining:

1. Assembly of an analytic framework by non-systematic review.
2. Framework analysis of patients’ experiences of the continuities of care.
3. Systematic comparison of organisational case studies made in the same study sites.
4. A cross-country comparison of care coordination mechanisms found in our NHS study sites with those in publicly owned and managed Swedish polyclinics.

5. 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 in-patient care.

Results

Starting from data about patients' experiences of the coordination or under-coordination of care we identified:

1. Five care coordination mechanisms present in both the integrated organisations and the care networks.
2. Four main obstacles to care coordination within the integrated organisations, of which two were also present in the care networks.
3. Seven main obstacles to care coordination that were specific to the care networks.
4. Nine care coordination mechanisms present in the integrated organisations.

Taking everything into consideration, integrated organisations appeared more favourable to producing continuities of care than were 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 larger scale. Ownership differences affected the range of services to which patients had direct access; primary care doctors’ managerial responsibilities (relevant to care coordination because of its impact on GP 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 coordination, 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.

498 words

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Abbreviations

ADL	Activities of Daily Life
A&E	Accident and Emergency Department
ALoS	Average length of stay
AHP	Allied health professional
ANP	Advanced nurse practitioner
APMS	Alternative Provider Medical Services (type of primary care provider contract, NHS)
AREA	Allocation of Resources to English Areas (NHS finance allocation system)
BMA	British Medical Association
CBT	Cognitive behavioural therapy
CCG	Clinical Commissioning Group
CCM	Chronic Care Model (the 'Wagner model')
CHS	Community Health Services
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
CMHT	Community Mental Health Team
COPD	Chronic obstructive pulmonary disease
CPN	Community psychiatric nurse
CRUSE	Bereavement charity ('Cruse' is a biblical term for a jar of oil.)
DES	Directed enhanced service
DDR	Deutsche Demokratische Republik (former East Germany)
DGH	District General Hospital
DH	Department of Health (England)
DN	District nurse
DRG	Diagnostic-related group
DVT	Deep vein thrombosis
ECG	Electrocardiogram
ED	Emergency Department
EHR	Electronic health record

EMR	Electronic medical record
FFS	Fee for service (unit of payment)
GMS	General Medical Services (NHS contract for general practices)
GP	General practitioner (not ‘general practice’)
GPSI	GP with special interests
H&WBB	Health and Well Being Board
HCA	Health care assistant
HREP	Health Reform Evaluation Programme
HSDR	Health Services and Delivery Research programme
HMO	Health maintenance organisation
HRG	Healthcare Resource Group
INR	International normalised ratio (measure of blood clotting tendency)
IV	Intravenous
MBS	Medicare Benefits Schedule (Australia)
MDT	Multi-disciplinary team
MRI	Magnetic resonance imaging
NGMS	‘New’ General Medical Services (post-2004 NHS contract for general practices)
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NP	Nurse practitioner
OPD	Out-Patients Department
OOH	Out-of-hours service
PACE	Project for Advocacy, Counselling and Education
PARR	Patients At Risk of Re-hospitalisation (risk stratification tool)
PCMH	Patient-centered medical home (US primary care provider)
PCT	Primary Care Trust
PE	Pulmonary embolism
PHC	Primary health care

PHCC	Primary Health Care Centre (Sweden)
PMS	Personal Medical Services (NHS contract for general practices)
PRISMA	Programme of Research to Integrate the Services for the Maintenance of Autonomy (Canada)
OT	Occupational therapy/therapist
QALY	Quality-adjusted life year
QOF	Quality and Outcomes Framework (for NHS general practices)
RCGP	Royal College of General Practitioners
RCT	Randomised controlled trial
RQ	Research question
SDO	Service Delivery and Organisation research programme
SF36	Short-form 36-item health survey
SHA	Strategic Health Authority
SIPA	Services intégrés pour les personnes âgées fragiles/Integrated services for frail elders (Canada)
SLL	Stockholms läns landsting/Stockholm County Council
SLSO	Stockholms läns sjukvårdsområde/Stockholm County Healthcare Provision
TLAP	Think Local Act Personal scheme (for personal health budgets)
WHO	World Health Organization

Glossary

Italicised terms originate in languages other than English.

Buurtzorg	Not-for-profit organisation providing team-based community care, with GP support and a minimal management infrastructure (Netherlands).
Captant	Professional (typically doctor) who deals with a patient first in each new episode of care, and who by default becomes the first *de facto* professional coordinator of the patient's care.
Care coordination	Activities which combine different providers' separate inputs into a coherent programme of care for a patient.
Care network	Stable set of linkages between separate provider organisations, for the purpose of jointly providing care (e.g. by implementing a care pathway).
Clinical coordination	Care coordination at the level on the individual patient.
Consultation model	Method of care coordination in which all referrals are made by the professional (typically doctor, but possibly nurse practitioner or similar) who coordinates a patient's care. Hence the coordinating 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 healthcare needs, that she has access to.
Continuity of care	Portmanteau term for one or more of the following dimensions ('continuities') of care. See the separate entry for each. 1. Cross-sectional continuity 2. Longitudinal continuity 3. Flexible continuity 4. Continuity of access 5. Informational continuity 6. Relational continuity
Cross-sectional continuity	Managing a patient's complex health conditions as a totality in

	light of how they, and the corresponding interventions and care, interact. Synonyms: 'clinical', 'comprehensive', 'holistic', 'management' or 'therapeutic' continuity or care.
Falsificationist (method)	Method of testing hypotheses by means of seeking evidence that would show them to be false. Hypotheses which survive this test are provisionally accepted, pending any future discovery of new evidence that disproves them.
Flexible continuity	Responsiveness of care to changes in the patient's circumstances.
Governance structure	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.).
GP	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).
Health Passport	Patient-held summary of the patient’s current health status, medication and other information that a new healthcare provider is likely to need to know.
Husläkare	Primary care doctor (Sweden).
Informational continuity	Extent to which a patient's care plan is decided on the basis of all 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, i.e. 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	Maintenance of planned treatment when providers change (e.g. through shift changes, staff turnover, patient transfers).
Nårsjukvard	Health centres typically offering planned day surgery, other day treatments and limited in-patient care besides primary care

	(Sweden).
Nested frameworks	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 coordinating (or managing) body	Group established to coordinate the activities of a care network. Depending on circumstances the coordinating body may be a separate organisation, 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 coordinating 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 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. (On 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 salaried employee, professional partner or ‘free professional’ working alone (hence including GPs as a special case.)
Provider	Individual professional or organisation caring for patients.
Provider organisation	Organisation (professional partnership, bureaucracy, cooperative), 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') where it was actually implemented.
Relational continuity	Ongoing contact with the same carers (care coordinator, informal carers, clinicians) during the care process.
Vårdcentral	Swedish polyclinic, publicly financed (but diverse types of ownership) and employing primary care doctors and other

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

Scientific Summary

Background

Nearly a sixth of NHS patients have multiple morbidities. They usually need more extensive and varied healthcare 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 coordinate 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 healthcare providers make the coordination 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. Continuty of Access
5. Informational
6. Relational (or 'personal')

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

1. Care coordination by patients themselves.
2. Provider organisations internally coordinating the services that they provide.
3. Care networks coordinating the separate provider organisations.

4. At local health system level, organisations such as CCGs attempting to coordinate 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 coordination 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 coordination 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 coordination, and therefore continuities of care, than coordination by care network. This research therefore examines the ways in which care coordination at the *clinical* level might be promoted by *organisational* integration; that is, a unified organisational structure to coordinate and provide the different services comprising complex care.

Objectives

The research questions were:

RQ1. What difference does the integration of primary care into hierarchical governance structures make, compared with network governance, in regard to:

a. continuity of primary care (horizontal integration)?

b. substitution of primary for secondary care (vertical integration)?

c. the availability of management information about unit costs of care episodes and management costs?

d. diversity of primary care services?

RQ2. In the case of hierarchical governance, what difference does ownership make?

RQ3. 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?

RQ4. Do the answers to RQ1, RQ2 and RQ3 tend to support or refute the predictions (outlined above) about the differences between networked and hierarchical governance in regard to continuity and integration of primary care?

RQ5. What are the implications of the above for managerial practice in primary care?

Methods

Multiple-methods design combining:

1. *Assembly of an analytic framework* by non-systematic review of existing research. This directly contributed to answering RQ4, and indirectly to answering the other RQs.
2. *Framework analysis of patients' experiences of continuities of care* in a maximum-variety sample of care coordination 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 coordination mechanisms described in the organisational case studies. This contributed to answering RQ1 and RQ4.
3. *Systematic comparison of organisational case studies* made at the same study sites. For each site, a case study was produced describing coordination mechanisms at organisational, care network and local health system governance level. Applying the above analytic framework, we systematically compared coordination mechanisms across sites; that is, across a variety of organisational and network structures. This contributed to answering RQ1, RQ2, RQ3 and RQ5.
4. *A cross-country comparison* of care coordination mechanisms found in our NHS study sites with Swedish polyclinics, which have primary care coordination structures not found in the NHS. We did so by means of constructing organisational case studies similar to (3) above in selected Swedish polyclinics and systematically comparing them with the NHS case studies.

This contributed to answering RQ1, RQ2 and RQ4.

5. *Analysis and synthesis* of data using an 'inside-out' analytic strategy'. Starting from patients' experiences of care coordination 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 in-patient care.
2. For patients:
   (a) 65 years old or more.
   (b) With complex healthcare needs, defined as having at least two of a list of chronic conditions.
   (c) Receiving care for at least one year before the study from at least two provider organisations.
   (d) Living in 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 light of the empirical findings.

Results

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

1. Consultation model of care coordination.
2. Interdisciplinary care teams (often several in parallel).
3. 'Virtual ward' or 'hospital at home' models of care, though 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. Co-located services.

The main obstacles to care coordination within the integrated organisations were:

1. Professional silos, with rivalries between occupational groups.
2. Discrepant IT 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 coordination comprised:

1. Information flows which 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 coordination, particularly when patients were discharged from hospital.
3. Means tests for services, which created bottlenecks that obstructed care coordination.
4. Capacity mismatches between successive providers in the care process.
5. Weak or absent inter-organisational 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 coordination by:

1. Creating line-managerial accountability for care coordination 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 inter-organisational boundaries.
3. Co-locating 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 sub-units or services to secede (in a network organisations can unilaterally decide to join or leave).
6. Having one workforce provide both clinic- (e.g. GP surgery-) based 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 coordination of primary care with in-patient 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 either to co-locate 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 coordination 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 immediately to be referred from their general practice to other providers. Care network coordinating bodies exist partly as a workaround for the ensuing problems of care coordination. Our evidence (frequently evidence of its absence) suggests that a care plan, shared among providers and with the patient, is an important means of coordinating a patient's care and strengthening its continuity. Recording and sharing a care plan requires, however, information systems which 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 coordination, 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 cooperative, 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.

1984 words

Plain English Summary

Many NHS patients especially frail older people, have what we call 'complex needs'. That is, many and varied long-term conditions which need treatment and care from more than one service at once (general practice, community nursing, social services etc.). The better coordinated these services are, the more likely it is that these patients will be able aware of, and able to use, the range of support needed to maintain their health. This helps people avoid further illness and hospital admissions, and 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 GP-led health centres, 'case management' (where a community matron or similar coordinates patients' care and (especially in London) 'polyclinics'. We wanted to find out how these approaches compare in terms of improving the coordination of patient care across the range of services. We did this by interviewing patients with complex healthcare needs, their carers (where appropriate) and their health/social care workers to find out what helps coordinate 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 coordinating care for patients with complex care needs. This suggests that combining general practice and community health services into one organisation is likely to coordinate care better than the current separation between general practice and other health services.

176 words

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BACKGROUND

1 The Policy Context

Nearly a sixth of NHS patients have multiple morbidities.[1] They usually need more extensive and varied healthcare inputs than one clinician can provide, besides 'social' care, informal support and sometimes secondary care, all adjusting to changes in their circumstances or health. Coordinating all 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 two 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, 'under-coordination most severely affects the poor and vulnerable',[4] especially those with long-term conditions and multiple illnesses such as older patients and patients with both physical and mental health problems.[4] Complex care that is sufficiently coordinated to avoid such problems is often called 'integrated' care, meaning 'integrated at the patient or clinical level'.[5] It is more effective, reduces medical errors or duplicate tests, and increases the likelihood of post-hospital follow-up care and patient satisfaction.[2,6]

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

1.a 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.[7]

‘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 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,[8,9] nor 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 out of, the NHS. After 1999, Primary Care Trusts (PCT) combined local networks of independent general practices[10] with direct PCT management of CHS, until the latter were hived off in 2009. Although official reports since 1956[11] have criticised this ‘tripartite division’ between general practice, community and hospital services, and social services it persists, producing at times fragmented, duplicated services.[12] Correspondingly discrepant managerial practices and regulations impede collaboration,[13] especially between NHS and social services with their different eligibility, co-payment coverage and rules.[14]

The problem of how to coordinate and maintain the continuity of care provided by multiple organisations therefore also persists.[15] In recent years, though, 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.

1.a.i Care integration

A consequence of the successes of NHS acute care, improved living conditions and lifestyles is an ageing population, an increasing prevalence of multi-morbidity 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,[16,17] as were delayed discharges from hospital.[18] Patients less satisfied with access to their general practice appeared to be more likely to use EDs.[18] NHS policy came to assume that more integrated care might address all these problems, reducing the numbers of unplanned admissions and reducing the length of hospital stays generally.[18]

1.a.ii 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.[19] 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 £1.9bn of NHS budgets be transferred to joint local authority and NHS control; however, this ‘Better Care Fund’ has (in mid-2014) not yet been created.

1.a.iii 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:[20]

- New general practice contracts (PMS, ‘New’ GMS, APMS).
- Nurse- and AHP-led general practices.

- Extending GP cooperatives 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 and community health services.[10] Technical specialisation[21] and providers' increasing organisational diversity both exacerbate the difficulty of coordinating care provision across multiple providers, fragment organisational responsibilities and increase the scope for service duplication.[22]

1.a.iv GPs as commissioner-coordinators

Since the GP fundholding scheme (1991), NHS policy has increasingly made GPs responsible for care coordination: 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 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 community health services. 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.[23]

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 coordinating their own care.

1.b 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 (*Table 1*). While a few of them did attempt to organisationally *integrate* GPs or general practices with other services, most nuanced the tripartite structure and promoted care coordination across the (adjusted) boundaries within it. The policy advantage of framing ‘integration’ as inter-organisational coordination or collaboration was that it challenged neither the tripartite structure nor structural changes introduced for other policy reasons (e.g. marketisation).[24,25]

Table 1: Care integration policies, in ascending order of organisational integration[20,26–37]

- Co-location
  - Health centres
  - ‘Polysystems’ (London)
- Care Networks
  - Multi-agency 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)

1.b.i Co-location

A physical rather than organisational remedy was to co-locate services. After Dawson's report, the next main innovation (1935) was the Pioneer Health Centre at Peckham. This co-located preventative activities (physical exercise, swimming pool, games, workshops), a day nursery, cafeteria, laboratory, general practice and (after 1946) an infant's 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 co-payments.

From the 1950s the Ministry of Health supported the construction of health centres in which to co-locate general practices with CHS, dental and hearing services. Whilst many were built, they remain far from universal. Despite the Cumberlege Report's[38] advocacy of area-based community nursing teams, the co-location, or at least attaching, of CHS staff to general practices became widespread over subsequent decades. Less often, social workers were also co-located to general practices, and in a few areas social care teams came under joint NHS and local government management.[39]

1.b.ii Stronger coordination

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',[40] a key element in the Darzi report.[41] 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 community health services and GP-led health centres or 'polyclinics'.

Darzi[42] argued that co-locating GPs with CHS and social services (or, failing that, using IT to link services) would promote service coordination:

> 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.[42]

The *Next Stage* review (2007) promised the creation of 150 'GP-led health centres', open to patients not registered with the GPs (which also addressed the finding that, on the basis of AREA-weighted populations, deprived populations were seriously under-doctored). 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.[43] To some observers this sounded 'like a GP surgery bolted on to an independent sector treatment centre'.[44] The proposal to offer APMS contracts to providers running these centres led many people, including the BMA, to perceive, and hence oppose, the plan as extending corporate provision of NHS-funded primary care.[43,44]

While the Government was quick to announce proposals to develop 'polyclinics' across the country,[44] the concept remained vague with no specific blueprint beyond Darzi's initial vision. Developments in practice were more limited and ill defined.[43] 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.[45–47] They proved expensive and many attracted few patients, giving poor value for money.[48] In London, however, the number of walk-in patients far exceeded expectations, although without reducing pressure elsewhere in the system.[49]

1.b.iii London polysystems

NHS London took the Darzi centre idea a step further. *A Framework for Action*[50] set out plans for between five and ten 'polyclinics' to be established. The favoured option was locality-based 'polysystems', either physically co-located 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',[51] challenged the assumption that polysystems would reduce ED attendances, and questioned the lack of detail on costs and the implications for hospital survival.[52]

A large-scale evaluation of London polysystems[49] was commissioned, but remains unpublished. Its interviewees equated service with system integration, and both with multiple co-located 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 ten polysystems actually appeared in London, many built on existing developments[49] and more limited than originally envisaged,[45] for example developing single community-based services (for COPD, back pain); a co-located GP and walk-in centre with some out-patient consultations; and a new general practice in a hospital ED.

It proved difficult to change GP referral patterns, leading to under-utilisation 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 duplication and disconnection of services. There were also examples of co-located 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 co-locating 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 co-located 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.

Yet 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 coordination. Co-locating 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. Co-location 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, hence less collaborative); and different IT systems. While patients liked the option of accessing many services on the same site, few actually used more than one during each visit.

1.b.iv 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 healthcare providers who constructed care pathways across organisational boundaries,[53] in ascending size from case management schemes to inter-organisational care teams[54] to care hubs, federations of general practices and NHS–local authority ‘partnerships’. Case management was often embedded in these networks, indeed was the focus of six of them.[55] Since 2010, NHS policy has encouraged the development of federations of general medical practices that share certain other primary care services such as GPSIs, 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, long-term condition managers and social workers work as one team with a cluster of practices. The ‘Virtual Ward’ model is more vertically oriented, with (for example) 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 undertake inter-sectoral health promotion and foster inter-organisational care coordination,[14,24] particularly for frail older people. Inter-organisational coordination often appears strongest at the top managerial level and more ad hoc at an operational level.[56] However, there are exceptions. Care trusts come closer to organisational integration. In Torbay, managerial structures and budgets for community health services 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 (TLAP) scheme is piloting integrated health and social care personal budgets.

1.b.v A bi-partite system

Northern Ireland has a bipartite rather than 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.[57] 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).[58] Nevertheless, ‘cultural’ differences inherited from the constituent services, such as the dominance of health interests, persisted for many years.[57] General practices remain separate organisations.

1.c 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 cooperate, and problems of rurality.[59] Department of Health interest in polyclinics and care closer to home was stimulated partly by knowledge of organisations in mainland Europe that enhance care coordination and of Kaiser Permenante in the USA.[40] Studies of developments aimed at integrating rehabilitative care come mostly from Australia, Belgium, Canada, the Netherlands, Norway, Sweden, the UK and the USA.[13]

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 coordination have been quite convergent, focusing on the horizontal coordination of primary care through care networks, care coordination tools, case management, joint working and decentralising and/or pooling of budgets.[59] 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 NHS introduced policies to reinforce group practice and promote coordination 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* (from three to ten 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 three to eight 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).[60] Primary care centres have been introduced in Spain since 1981 for the purpose of co-locating 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 NP by algorithm, based solely on patients' own description of their symptoms (clerks do not diagnose).

German efforts to improve care coordination have concentrated on integrated care schemes

(*Integrierte Versorgung*), in part reconstituting models developed in the DDR but abolished on reunification:

> **Manager, German Association of Social Health Insurers**: [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.'*

An 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.[61] 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 healthcare 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 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 coordinators. 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 SIPA model, and in a different way the PRISMA project, in Canada promoted multidisciplinary teams (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.[62] As in Germany, highly commodified[63] provider payment systems have obstructed care coordination 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. 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.[64] Fragmented sources of primary care funding and the prevalence of single-handed GPs further obstruct care coordination.[65]

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 2*).

Table 2: Integrated primary care organisations: Governance options[26,27,31]

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 cooperatives (UK)

According to country, polyclinics may be operated by municipalities (e.g. Sweden, Finland, Catalonia, former Yugoslavia[66]), health ministry (Portugal), regional government (Italy), employers (Russia, Germany) or hospitals (Russia).[67] Amalgamated primary care providers have been used to coordinate primary medical care 'horizontally' with (other) community health services 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 out-patient 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 as symbolic of the Soviet system,[68] 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.[69,70] *Vårdcentral* primary healthcare centres are hierarchical governance structures where municipally employed primary care doctors, nurses and therapists are managed in one unit and subdivided into multidisciplinary teams. 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 healthcare, 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.[71–73]

1.d What research has so far contributed to altering policy and practice

As the next chapter shows, there is a 'babel'[74] of research on healthcare 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 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 coordination of care.

2 Care Coordination and Integration: Process and Structures

Overall, research and policy discussions about care integration are a conceptual mess, lacking standard categories, concepts or terminology.[24,75,76] ‘Persuasive definitions'[77] often take the place of taxonomy. In this chapter we designate which concepts of ‘integration’, ‘coordination’ and ‘collaboration’ this study will use. We outline a realist synthesis[78] (see *Section 4.b*) of existing research findings about which mechanisms, and under which organisational conditions ('contexts'), appear to promote (or obstruct) to policy outcomes of care ‘integration’, ‘coordination’ and ‘continuity’, so defined. In this way, we derive hypotheses amendable to empirical testing.

We follow the 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’[79] – a ‘patient-centred’ approach.[80]

2.a 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,[81–83] we differentiate six main continuities (or discontinuities) of care at the clinical level:

1. *Cross-sectional continuity* (synonyms: ‘clinical’, ‘comprehensive’, ‘holistic’, ‘management’, 'therapeutic' continuity[35,83–86] denotes managing a patient’s complex health conditions as a totality in light of how they, and the corresponding interventions and care, interact, so as to produce a single, consistent care process to meet all the patient’s healthcare needs.[87] This is critical when more than one provider is needed at a time.

2. *Longitudinal continuity*, which is planned contact and treatment being maintained either when providers change (e.g. shift changes, staff turnover, patient transfers), or maintaining contact with the same provider, measured by examining rates of overall contact or gaps in contact,[88,89] proportion of contacts with the same provider, or assessed subjectively from patients’ own accounts.[90]

3. *Flexible continuity* (‘developmental’ continuity, sometimes[91] subsumed under ‘management’ continuity) refers to care responding to changes in the patient’s circumstances,[81] hence that somebody reviews these circumstances and changes the care plan accordingly.

4. *Continuity of access* refers to how complete and accessible the range of available services is, compared to the patient’s healthcare needs.[85,90,92]

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.[83,84,86,91] This requires an information system that supplies clinical teams with feedback and decision support (e.g. access to or implementations of guidelines).[93]

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 coordinator, informal carers, clinicians)[83,86,91,94] during the care process, so that these carers come to know the patient’s medical history and personal circumstances in the round,[86,95] and, crucially, build up relationships of trust.[96–98] Then the patient is more likely to engage with each clinician, to disclose any psychosocial problems[99] and to adhere to an agreed treatment plan.[100,101] This particularly appears to be the case for patients with more chronic or serious conditions, psychological or social problems.[75,95,102–105]

These continuities improve the outcomes of care and its safety[4,36,81,106] (although Gray cites counter-examples[107]); patient satisfaction,[81,84,88,91,92,96,102–104,108–111] adherence[84,100,101,112,113] and capacity for self-management; and the efficiency of service provision.[106,112–115] The balance of evidence suggests that they may reduce the unscheduled use of secondary care.[106,116] 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;[83] 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 importance[117]).

2.b The patient: Producing and experiencing continuity of care

2.b.i ***Patients as care coordinators***

Most patients expect to have a role in coordinating their own care

[9191]; and must when health professions fail to do so.[6] (*Appendix 1* elaborates some of these points.) Wagner's 'pyramid'[118118] 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.[119,120119,120] An important way in which patients coordinate 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.[121,122121,122]. Formal services can also help patients self-manage their care (e.g. by helping people with psychiatric problems manage their financial affairs[123123]). Personal budgets supplement the patient's resources, strengthening the patient's role as care coordinator. 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.[124124]

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Yet there are practical limits to patients' self-coordination of their own care. One is how far patients can or will travel to receive care,[125] 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.[126] 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 gender to the patient.[127] The patients most needing coordinated care are often those whose multimorbidity[1] and multiple medication make it hardest for them to coordinate their own care[6] and for whom hospital admission is less discretionary.[128] The severity of the condition and the level of distress predict help-seeking for mental health problems.[129] Self-management programmes also have, in some contexts, high drop-out and refusal rates (10% and 51% respectively in a Spanish study).[130] 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.[131,132] 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 coordinating their care then passes largely to their healthcare providers.

2.c Coordination: The production of continuity

2.c.i ***Processes and structures for care coordination***

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

1. A person coordinates 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 emergency department etc.).
4. Where needed the patient is transferred to further providers (community health services, psychiatric care, hospital etc. as relevant).
5. These 'second-responder' providers then provide and coordinate 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 out-patient, in-patient 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 healthcare 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.[34] The increasing technical, hence occupational, specialisation of healthcare 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.[6] Studies of these processes (especially experimental studies) have tended to concentrate on chronic disease (cardiovascular disease, diabetes, asthma, COPD, AIDS/HIV); mental health, including substance abuse; and care of the elderly[133] – increasingly prevalent conditions[93] 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 process[134] and make the patient’s transitions between these providers as easy, prompt and non-disruptive as possible.[81] That is, the greater is the need for care coordination[6] as a ‘continuity mechanism’,[81] for ‘continuity is how patients experience integration of services and coordination’.[91] Clinical care coordination requires the following steps:

1. A care coordinator (an individual or team) combines different providers’ separate inputs, with a clear division of labour between them, into a coherent care process[14] 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 coordinator maintains an ongoing relationship with the patient[25] (to produce relational continuity).
3. The patient’s care plan, which includes social care,[75,91,135] 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 coordinator reviews the patient's circumstances and, if they change, alters the resources or services offered (to produce flexible continuity).
5. The patient has access (often facilitated by the care coordinator) 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 coordination of care.

However, the *structures* through which health systems undertake care coordination are nested. Working 'outwards' or 'upwards' from the patient level, the production of continuity of care typically involves four organisational levels:[136,137]

1. Patients coordinate their own care.
2. Coordination within one provider organisation (general practice, community mental health trust etc.), which may involve a named care coordinator.
3. Inter-organisational coordination through a care network of separate provider organisations[53]; or 'virtual' integration (as in most NHS 'Integrated' care schemes). Horizontal coordination is that of multiple primary care providers, vertical coordination that of primary with secondary care.[137] (We do not equate 'vertical' with 'hierarchical' and 'horizontal' with 'network'.[123])
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.[138]

Evidence is accumulating that care coordination depends on the interaction of structures at all these levels.[93,139,140] 'Coordination structures' have 'consequences for personnel' and these have 'consequences for clients'.[34] For instance, Wagner's well-known model[118] views chronic disease management as requiring six 'pillars': community resources and policies, healthcare 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, both for single diseases and multi-morbidity.[93] A systematic review[141] 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 healthcare practice), the evidence suggested that implementing interventions based on the model appeared to support improved healthcare outcomes. Evidence of the economic impacts of 'integrated' care is sparse and, overall, inconclusive.[142] More studies focus on general practice 'characteristics' (number of doctors, team climate etc.) than on how such practices are organised.[143] In this research we focus on, and contrast, the *intra*- and *inter*-organisational levels of care coordination.[144]

2.d First-responder provider organisations

An episode of complex care begins when a patient accesses a 'first-responder' healthcare provider where a clinician (typically a primary care doctor or nurse practitioner[65,145]) first assesses the patient. In light of this assessment (for many people with complex care needs, formal risk assessment), this health worker transfers the patient to others, either because the latter have more 'appropriate' expertise,[24,146] including perhaps in care coordination,[147] 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 coordinator. However, a health worker who sees herself as the care coordinator may trigger a conflict when the professional to whom she sends the patient sees that as transferring full responsibility for the patient's care to *him,* especially when the two prefer very different treatment methods.[148] 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 coordinator 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.[148]

2.d.i ***Care plans***

Care plans are the standard way to assemble and define flexible, individually tailored combinations of services for each patient,[25] possibly including elements of self-management,[65] patient education and planned communication with clients and families (e.g. through joint consultations and reminders).[64] As a means of coordinating care[149] 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,[137] which facilitate informal relational coordination in hospital settings[150,151] 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 models[4]), 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 review[152] 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,[145] for instance mental–physical multi-morbidity,[153] involves clinical complexity that is hard to predict and difficult for protocolised, routinised or pre-planned healthcare processes to accommodate.[13,148] Many of the studies underlying evidence-based guidelines were designed expressly to exclude patients with co-morbidities. A perception of receiving 'production-line' treatment may make patients less compliant.[154]

2.d.ii ***Coordination mechanisms within a single organisation***

'Organisational integration' means that a single organisation undertakes these activities, rather than separate organisations.[137] Patients' care is coordinated by a unified management structure that applies a single set of objectives when planning, financing and delivering (producing) care.[21] Within integrated organisations, three mechanisms for coordinating patient care are widespread:

1. The consultation model
2. Line management
3. Internal inter-disciplinary teams

In practice these mechanisms often coexist, not always comfortably.

The **consultation model** of care coordination[134] involves both a '*captant*' profession that focuses on the patient's care as a whole, in the round, and a complementary set of professions who focus on more specific tasks.[148] Typically, the captant health worker (classically a GP) transfers or refers patients to other professionals with more ‘appropriate’ expertise[24,146] who, having made their contributions, return the patient to 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 coordinator, unless 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 coordinator 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 coordinator 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,[155] assisting collaboration[13] and care coordination. Besides using formal care plans (see above), an ideal-type bureaucracy would coordinate care by standardising:

1. Information transfer, producing informational continuity[6,83,136,156,157] 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, e.g. common hours of work.[90]

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 inclusion[89] requires that, say, assertive outreach team staff have sufficient time to build and maintain working relationships with their clients.[158] Corporations and public bureaucracies[155] can exploit the formalisation and standardisation of work processes to routinise, automate and de-skill work, using cheaper, more flexible staffing arrangements, and to that extent increase labour productivity. Examples of this tendency include the introduction of call centres,[159–161] telephone-based care management[161] and the development of case-load norms for community matrons.[37] 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.[162] However, the larger the provider organisation, the more difficult relational continuity might become to maintain.[76]

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, though, healthcare providers typically accommodate specialised care by developing an organisational structure[163] in which uni-professional hierarchies (‘semi-detached’ professional ‘silos’[164]) coexist in parallel, formally linked to each other and to ‘general’ management only at senior level via ‘hybrid’ clinical managers.[165] Each profession tends to cultivate the habit of other professions referring to them ‘good’ patients ‘appropriate’ to their established ways of working.[148] Certain professions see their role as limited to a determinate part of the care pathway; others see it as overseeing the whole patient journey.[148] In such organisations inter-professional demarcations and rivalries,[57,166,167] reflecting ‘turf wars’ over status and resource control,[34,168] 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 coordinate care interventions.[149] 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[123,148]). Doctors especially are reported[169] to resist what they perceive as over-management, at times equated with any non-medical management, which may actually reduce doctors’ ‘citizenship’ and ‘behavioural commitment’. However, managerial and inter-professional links created for practical operational purposes, and focusing on the health outcomes of collaboration, have the opposite effects.[152,170] In the USA, HMOs spread only by diluting the strong management and vertical integration of the likes of Kaiser Permanente.[171] Under the admitting-rights model or where primary medical care is organised on speciality lines (e.g. Germany, France[148]), the self-image of the doctor, even in primary care, is more as a specialist expert than as care coordinator. A multiple case study[172] reported GPs as being reluctant to relinquish what they saw as their central role in the clinician–patient relationship and wondering whether inter-professional working would reduce their autonomy.

Internal inter-disciplinary teams can coordinate care across professional 'silos' even when the care coordinator has no line-management authority over the other professionals[136] (a 'project team' arrangement, common outside healthcare[173,174]). 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 review[24] describes interdisciplinary teams as a prerequisite for effective, integrated care of older people. A care team can undertake assessment and care planning, implement disease-specific guidelines and support self-management,[65] a collective care coordinator role.[148] The team may have a nominated coordinator who negotiates and agrees care plans with the other team members,[175] for instance at case conferences or the equivalent. The impacts of team care coordination 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.[65]

Cooperation between team members depends on what place each occupational group has within the care pathway.[148] Many studies suggest that aligning 'cultures'[176] 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 relationships[177–179] and personal affinities among team members.[180] Good-quality information sent to other professionals was reported, in a French study,[148] to improve relationships between the latter and the referring doctor. Especially when the team is being set up,[175] it is necessary for its members to commit themselves to shared assumptions about their roles, ways of interaction and common tasks[123] (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.[176] The more varied the services or occupations involved, the harder it is to coordinate a team.[123] Scores for satisfaction, continuity of care and access to care are higher in general practices where staff report a better team climate.[181] One would expect coordination 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 co-morbidities).[182] Where the patient's carers remain the same, relational continuity – in effect, the patient herself transmitting information informally – can to a limited extent substitute for weak informational continuity in IT systems.[81] Team coordination may improve patient well-being, but it does not necessarily produce cost savings.[65]

2.d.iii ***Vertical integration***

Vertically integrated 'systems' combine primary with hospital care, for instance when hospitals acquire physician groups,[183] 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'.[21] An extensive study[25] found that the care coordination 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 coordinating 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.[72] found that for 11 major care groups, Kaiser Permanente (which integrates health insurance, hospitals and ambulatory care doctors) had admission rates and ALoS around a quarter of NHS levels (in 2003).[71] The researchers attributed these effects to primary care doctors having an interest in keeping Kaiser 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 healthcare organisations:[21,34]:

1. Hierarchical governance or long-term relationships between organisations that approximate to that (e.g. micro-commissioning[56]).
2. 'Systemness',[21] i.e. continuity of care and provision by teams, enabling the substitution of less for more costly models of care. This is what Øvretveit et al.[34] call 'clinical integration', i.e. how well services are coordinated 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 coordinated across units).[87]
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 MRI scans) and minor procedures, there is some American evidence to support this assumption.[162] Substitution also avoids disruptive transitions between care settings. In England, GPSI dermatology services were more costly than hospital out-patient treatment, but had similar outcomes and better access.[184] The NHS 'Closer to Home' project was an hospital out-reach 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, although not care coordination or interpersonal quality of care. The new services only treated less complex conditions, although at a lower cost than the standard NHS hospital tariffs.[185] 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.[162]

2.e Transfer between provider organisations: Care networks

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

2.e.i ***Emergent networks***

Emerging from habitual referral or information flows,[13,53] a care network of interdependent providers[152,186] coordinates health, and often social,[187] care for a defined care group. Some call this 'virtual integration'. At their simplest, care networks may work by nominating 'link workers' as care coordinators for individual patients and/or care groups.[188,189] Through repeated use[148,189] or prior decision, such arrangements become normalised,[190,191] even to the point of developing formalised systems for planning and coordinating patients' care,[13] requiring 'a sound system of referrals'.[187] A Massachusetts study[192] 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. A systematic review[64] found that the care coordination projects with the greatest impact on health outcomes were (in descending order) those addressing relationships between service providers, clinical coordination arrangements, and infrastructural support for coordination. 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.[13] The greatest obstacle to care coordination is when key providers do not participate in the relevant care networks, which then lack links to other providers.[193] Successful programmes (e.g. SIPA, Integrated Care in Italy, PACE, SA HealthPlus) have tended to include geriatricians, primary care doctors or both.[24]

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 coordinator[194]; an important part, the RCGP says,[195] of what makes GPs 'generalists' and the traditional mode of care coordination 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.[196,197]

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 coach[198] has been employed to check that the patient understands and agrees with the proposed course of treatment, and to help in coordinating care among the (other) providers involved, including informal carers.[6] While 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.[86] 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% that the doctor had not asked about the patient's ideas on treatment and care (although 65% also rated their doctor(s) 'excellent' for 'Listening carefully to health concerns' and 57% as excellent in diagnosis); and 75% reported long waiting times for care (which included hospital care).[3] In past decades, GP referral notes to consultants often had meagre clinical content.[21] One study suggested that GP interest in care coordination tended to trail off once patients had accessed other, specialist providers.[182] US studies suggest that the increasing pressure on primary care doctors' time and the complexity of their tasks are practical obstacles to care coordination, which requires time between patient appointments[6]; 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.[181,199] 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.).[136]

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 coordinator. The case manager is often a primary care nurse[65,151,201,202] (e.g. nurse practitioner, 'community matron' or equivalent[37]), although allied health professionals, 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 coordinates care inputs from a range of services (a gatekeeper role[206]); 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 coordinator 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 coordination might also be undertaken jointly by individuals from different organisations.[208] (The cited studies however relate to individuals with depression rather than frail elderly people with mult-morbidity.)

In the USA, case management schemes reduced unplanned hospital admissions[32] and institutional placements of older people.[209] English case management schemes did not reduce unplanned hospital admissions[210] because the UK schemes were applied to patients living in their own home, who are known to make more use of secondary care (ED, OPD and in-patients) than patients in residential care[211] (the setting for the Medicare schemes). More effective case finding (also reported in Australia[212]) may 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 healthcare services and resources, patients' functional ability and levels of satisfaction, while reducing caregiver burden.[213]. A systematic review of RCTs for collaborative care[207] 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 healthcare, 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 **co-location** creates no new coordinating mechanisms and is only feasible when the providers' size and proximity permit.[123] Nevertheless, one might expect co-location to increase continuity of access and create opportunities for informal information exchange (informational continuity) between professionals and organisations.[64] Co-location facilitates,[152] but by itself is not sufficient to produce, collaboration across professional boundaries,215 including informal links.[13,81] Co-location can also be used to promote vertical coordination, for instance consultant consultations in the community and/or general practice ('outreach').[14] 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.[21] However, joint clinics do not necessarily promote relational continuity of care unless the division of labour between professions is 'carefully attended to'.[81] Indeed, co-location 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 co-location, evidence of the efficacy of telephone-based CBT for depression, agoraphobia and obsessive-compulsive disorder is now reported by randomised controlled trials.[217]

Internal multidisciplinary teams are readily expanded to become inter-organisational primary care teams, with the characteristics described above. Cultural continuity plays a major role in sustaining inter-organisational teams. Strong norms about the urgency of providing care at the onset of a stroke promoted the development of stronger, more formal coordination between ambulance and hospital services in Sweden. The absence of such norms appears to have contributed to the weak clinical coordination of post-discharge care found in both the English and Swedish health systems.[87]

2.e.ii ***Managed networks***

Emergent care networks may not necessarily work well or even form at all. In that case 'umbrella organisational structures' are required to create and coordinate them,[24,218] to establish a network identity, policies, structures, care pathways, leadership and resources[211] and 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'.[123] Care networks become managed (to prevent confusion, we avoid the term 'managed care network'). A network coordinating body can develop the sharing of:

1. *Care plans*, which in principle have much the same character, uses and content, with standardised and formalised proformas, as within integrated providers. In a care network, care planning requires an explicit division of labour,[152] defining each provider's accountabilities,[219] creating referral paths[133] and harmonising the different providers' working

practices. These arrangements have to be negotiated and agreed, possibly even formally, between providers,[13] since no higher manager exists to impose them. The coordination mechanisms so established typically include a single, coordinated 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*,[133] e.g. standardised assessment, triage and care planning instruments,[24] care protocols, periodic reassessments leading to early detection of health problems and consequent interventions,[25] and care plans shared across all the providers in the network. Activities such as geriatric screening and multidisciplinary assessment promote communication between providers[220] (informational continuity). A systematic review[152] 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*,[24,133] to align incentives among the network participants[176]; a 'demanding' form of cooperation that inevitably involves formal budgeting, possibly legal arrangements,[13] 'even common ownership of resources'.[24]
4. *Support activities*[176] (e.g. integrated data systems[24]), to produce informational continuity. Standardised electronic records have considerable potential to ease transitions between organisations[221] and to improve communications between them,[152] including at clinical level (e.g. case conferencing[64]), although the reality of health IT systems often falls short of this and IT systems are no substitute for oral communication.[221]

The network coordinating bodies may either be 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 coordinate the providers' work[62,219] 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'.[24] These activities require 'collaborative competence' in handling the problems that typically occur in collaboration.[123] Such competences include communication with other agencies (necessary for establishing clear roles and responsibilities), understanding other agencies' goals,[13] arbitrating over any disagreements and harmonising working practices across the member organisations.[189] 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,[13] 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 coordination may be more effective when focused on particular risk factors in co-morbid conditions or on functional difficulties in multi-morbidity.[223] Disease management schemes focus on patients with a single main diagnosis[65] and often include supported self-care[4] or the use of nurses as care coordinators. Often they develop partly because of the inadequacy of GP-based care coordination.[6]

US evidence suggests that disease management programmes improve chronic disease outcomes, but not necessarily care coordination.[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 coordinators providing mentoring for eight (somewhat overlapping) care groups, produced small improvements in SF36 scores.[65] 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 QALY per year at an incremental cost of £13,158 per QALY compared to a control group,[227] although this ratio easily met the 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.[32] 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 introduced managed care through HMOs foundered on the problems of information sharing, transaction costs and fragmented provider interests.[21] Managed care schemes have also been tried in Germany, but with limited success in recruiting patients.[61] Such schemes did reduce preventable admissions of over 65-year-olds compared with non-managed care, especially for the more ill patients,[128] thus helping control healthcare 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 seven 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 seven days after discharge than patients who were discharged in the usual way. Medicare is introducing bundled payments to physicians to coordinate patients' care on discharge from hospital and to provide a practice appointment 7 to 14 days after discharge.[233]

2.e.iii ***Barriers to care coordination by network***

Care coordination 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 healthcare networks in England and Canada.[152] Explanations of under-coordination 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'.[34] 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,[93] 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.[34] 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' coordination 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 coordination 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 multi-morbid 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.[186] Gradually, care networks may develop from information exchanges to running joint projects, changing 'systemic rules' and altering the health system as a whole.[235]

2.f Continuity, coordination, 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 coordination, and therefore continuities of care, than coordination by care network. An integrated organisation inherently pools the funds for the different areas of its work,[136] 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 labour[136] 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:

H1: In organisations which horizontally integrate services by means of the 'consultation model', patients will experience:

H1.a: High cross-sectional continuity of care;

H1.b: High relational continuity of care from the *captant* professional, but lower relational continuity of care from the *non-captant* professionals;

H1.c: High informational continuity of care; and

H1.d: High longitudinal continuity of care; but

H1.e: A level of flexible and access continuity of care which depends on the range of services integrated within that provider.

H2: In organisations which horizontally integrate services by means of an internal inter-disciplinary team, patients will experience:

H2.a: High cross-sectional continuity of care;

H2.b: Low relational continuity of care, unless the organisation is small;

H2.c: High informational continuity of care, but more within than between professional 'silos'; and

H2.d: High longitudinal continuity of care; but

H2.e: A level of flexible and access continuity of care which depends on the range of services integrated within that provider.

H3: In vertically integrated organisations patients will experience:

- H3.a: High cross-sectional continuity of care;
- H3.b: Low relational continuity of care;
- H3.c: High informational continuity of care;
- H3.d: High longitudinal continuity of care; and
- H3.e: High flexible and access continuity of care.

H4: In care networks which rely on virtual ('functional') integration patients will experience:

- H4.a: Low cross-sectional continuity of care;
- H4.b: Low relational continuity of care;
- H4.c: Low informational continuity of care;
- H4.d: Low longitudinal continuity of care; and
- H4.e: High flexible and access continuity of care.

H5: In networked disease management programmes patients will experience:

- H5.a: Low cross-sectional continuity of care;
- H5.b: Low relational continuity of care;
- H5.c: High informational continuity of care for the focal disease, but otherwise low informational continuity;
- H5.d: High longitudinal continuity of care for the focal disease, but otherwise low longitudinal continuity; and
- H5.e: High flexible and access continuity of care for the focal disease, but otherwise low flexible and access continuity.

H6: In case management through a network of providers, patients will experience:

- H6.a: Low cross-sectional continuity of care;
- H6.b: High relational continuity of care from the case manager, but lower relational continuity of care from other professionals;
- H6.c: Low informational continuity of care;
- H6.d: High longitudinal continuity of care; and

H6.e: 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 care networks preserve provider autonomy while maintaining safeguards against the uncertainties and opportunism found in markets.[21] 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 as to whether care coordination is likely to be easier, hence more fully achieved, through care networks or integrated organisations. Perhaps well-functioning care networks would coordinate care better than ill-functioning integrated organisations. This brings us to our research questions.

OBJECTIVES

3 Aims and Research Questions

3.a Aims

The aims of this study were to identify how the care coordination mechanisms in use in the main NHS services produced continuities and discontinuities of care; how NHS organisational structures constituted and constrained these coordination 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 coordination and continuity of care, and of widening the choice sets that they might consider for that purpose.

3.b Research questions

Our research questions (RQ) were therefore as follows:

RQ1. What differences does the integration of primary care into hierarchical governance structures make, compared with network governance, in regard to:

- (a) continuity of primary care (horizontal integration)?
- (b) substitution of primary for secondary care (vertical integration)?
- (c) the availability of management information about unit costs of care episodes and management costs?
- (d) diversity of primary care services?

RQ2. In the case of hierarchical governance, what difference does ownership make?

RQ3. 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?

RQ4. Do the answers to RQ1, RQ2 and RQ3 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?

RQ5. 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 research questions 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 research questions. As 'substitution of primary for secondary care' we count two things:

1. Partial substitution: shortening hospital lengths of 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 research questions in particular, these distinctions are important enough to warrant a verbal label.

We provide a glossary to clarify howwe have defined this and other commonly used terms in this field.

METHODS

4 Methods

4.a Design

Our methodological strategy reflected the nested character of the structures through which care is coordinated. We started from an analysis of patients' experiences of continuities of care, and then traced the organisational-level coordination mechanisms that produced those experiences. From the provider level we worked 'outwards' again to the care network mechanisms for coordinating care across different providers. Using Øvretveit, Hansson and Brommels' ideas[34] 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 coordination, from their own accounts, their healthcare records and administrative data. (Assessment of clinical outcomes was beyond the scope of this study.)
2. What care coordination mechanisms were available to that care group in that setting, and what barriers to coordination existed, knowledge obtainable from the practitioners and managers responsible for the care group.
3. What effects each of the observed coordination 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 coordination 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 thus follows Alexander and Bae's recommendation

[8080] 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 directly contributed to answering RQ4, and indirectly to answering the other RQs.
2. *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 coordination mechanisms described in the organisational case studies. This contributed to answering RQ1 and RQ4.
3. *Systematic comparison of organisational case studies*, applying the above analytic framework to a maximum-variety sample of care coordination mechanisms (organisational structures, care network structures, models of care, managerial practices). This contributed to answering RQ1, RQ2, RQ3 and RQ5.
4. *A cross-country comparison* of care coordination mechanisms found in our NHS study sites with Swedish polyclinics whose care coordination structures are absent from the NHS. This contributed to answering RQ1, RQ2 and RQ4.
5. *Synthesising* the above empirical findings so as to answer all four empirical research questions and correct our initial hypothesis about the relative merits of integrated organisations and care networks as means of care coordination (RQ4).

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 3* shows the methods, data and analyses for each research question.

Table 3: Research questions, methods, data, analyses

Research Question	Method	Data Sources	Analysis
RQ1. Differences between integrated and networked structures regarding continuity of care, substitution, vertical integration, cost	Systematic comparisons of organisations and care networks regarding: 1. Patterns of patient	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 coordination mechanisms reported in

Research Question	Method	Data Sources	Analysis
information, provider diversity	experience 2. Care coordination mechanisms		the organisational case studies
RQ2. Implications of ownership	Systematic comparison of care coordination mechanisms in corporate, professional partnership and publicly owned primary care medical services	1. Organisational case studies 2. Peer-reviewed secondary studies	
RQ3. Scope for managerial discretion and performance	Collate evidence across study sites of the scope and care coordination 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 coordination
RQ4. Predictive implications	Compare answers to RQ1, RQ2 and RQ3 with initial analytic framework	Aggregation of the above	Falsificationist: seek points where the above analyses falsify, qualify or corroborate the analytic framework
RQ5. Implications for managerial practice	Filter answers to RQ3 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 HREP, HSDR, NICE and DH Health Policy Programmes.

The underlying methodology was realist – not realist *evaluation*, since our research questions 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 coordination.[242] It was also falsificationist,[243,244] in that we first formulated a set of theories and hypotheses about care coordination, 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 NIHR CLAHRC for the South West Peninsula (PenCLAHRC). We worked with them before the research started on both a group and 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 & Development Offices for our case study sites and our original key informants.

4.b Initial explanatory and analytic framework

We assembled our initial analytic framework (*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 i.e. to:

1. Assemble theories about what organisational arrangements produce care coordination.
2. Identify care coordination mechanisms that appeared relevant to our focal care group but are not used in the NHS.
3. Operationalise our research questions, 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 coordination, 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 RAMESES recommendations[78].

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 key-words (e.g. 'care plan', 'primary care team'), hand-searching journal contents lists and snowballing back from one study to another often revealed more studies than automated searches (e.g. of PubMed, Google Scholar) of this conceptually and terminologically ill-defined literature did. We hand-searched journals dedicated to primary care coordination (e.g. International Journal of Integrated Care), those which focus heavily on clinical practice (but not necessarily care coordination) 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 coordination (e.g. Social Policy and Administration). We also hand-searched policy and think-tank websites (e.g. Department of Health, Kings Fund) for peer-reviewed studies.

Given our 'inside-out' analytic strategy, we started assembling the theoretical framework in chapter 2 by conceptualising (as others have[246]) 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 inter-disciplinary 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 study[247]) 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 sub-processes 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[164,248]. Research on inter-organisational networks reports what patterns of inter-organisational linkage appear conducive to effective and efficient inter-organisational collaboration in healthcare.[33,189,249] Some of the studies cited in chapter 2 appeared to describe instances of these wider organisational or network patterns. Then one could infer corresponding hypotheses about what effects these specific characteristics of primary care processes, organisational structures and inter-organisational networks would have on primary care coordination 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 research questions, we above all formulated hypotheses about what effects their context (integrated organisation *versus* network) was likely to have on the operation of mechanisms intended to produce care coordination and continuity. By the time the data analysis and synthesis were completed we had revised our initial framework in several ways, reported in *Section 11.a* (an ‘open-ended' analysis[251]).

4.c Case studies of organisational and care network coordination mechanisms

Applying the above analytic framework, we systematically compared case studies of a maximum-variety sample of care coordination mechanisms (organisational structures, care network structures, models of care, managerial practices). This contributed to answering RQ1, RQ2, RQ3 and RQ5.

4.c.i ***Sampling***

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

1. *Hierarchy, public ownership*. Ideally, this would be a single, integrated organisation providing primary medical care, community health services, mental health services and social care. However no such organisation existed in the NHS at the time of our fieldwork.

   a) 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.
   b) 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:
   a) General practices and CHS.
   b) 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 community health services in the same locality.
4. A *hybrid partnership, hierarchical and care network* structure: concretely, the standard tripartite NHS model (see *Chapter 1*), as a reference point.
5. A *privately owned medical practice networked with public community health services*. 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 coordination 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, DH and think-tank websites, and national media (especially the BBC and *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 coordination: networks of professional partnership general practices (e.g. CCGs, general practice 'federations')[44] 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 ten sites, at the loss of much time and effort gaining access to five, which together represented the main coordination structures that we needed to study.

These methods yielded the following sample of study sites in England. Three sites were whole counties, one part of a county, and the fifth 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 coordination 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 ten 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 an 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 coordinating care across provider organisations. Community health services 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 co-located separately managed services, with separate data holding but retaining 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 PCI, and developed into a community interest company. By the time of our fieldwork this network involved nearly all the general practices in the county, all the other healthcare providers, and social services.

3. **Sedgeton** was selected for its virtual ‘polyclinic’ housing *networked co-located services* – that is, organisationally separate community health, acute hospital out-patient and mental health services, all in one building, with mental health in-patient facilities next door. Links were developing with social care. The general practices referring to all 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 co-located 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 community health services 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 an NHS Treatment Centre, 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 (*Chapter 2*), *Table 4* summarises which structures coexisted. In each row, the bodies listed in the 'Care network' column coordinated 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 4* brackets them together {like this}.

Table 4: 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	1. CHS 2. Hospitals

		(referral hub)	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. Integrated primary care teams 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 person's community mental health team 3.	1. {CHS + hospitals + social care combined} 2. Mental health
Fivecastles	Corporate hierarchy	1. Multi-agency group 2. 'Gold standard' palliative care teams 3. Preventive health and social care providers network	1. {CHS + hospitals combined} 2. Mental health 3. Social care

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 5.*

Table 5: Organisational informants

	Eastmere	Whinshire	Sedgeton	Tarrow	Fivecastles
General practice (GPs, other staff)	2	3	2	2	4
Care network coordinators	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

4.c.ii ***Data collection***

Data were collected from informant interviews (using the schedule in *Appendix 4*) and managerial documents. Unless the interviewee requested otherwise, all interviews were digitally recorded and professionally transcribed, and interviewees offered the chance to correct their transcript. Our findings chapters 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, since they were best placed to say which documents were locally seminal. We also collected professional press reportage.

4.c.iii ***Initial analysis***

We collated data about each organisation’s and network’s care coordination mechanisms against the relevant headings in the analytic framework (*Table 6*), adjusting these categories when necessary.

Table 6: Data collation framework, organisational case studies

Main theme	**Sub-theme**
Care coordinator(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
Coordination mechanisms	Regular meetings
Managerial and clinical action and discretion	Ethos and leadership
	Care process redesign
	Cost
Substitution of primary for secondary care (vertical coordination)	Admission avoidance, early intervention
	Discharge planning
Context	Policy imperatives
	Diversity of providers/services
	Ownership – higher level controls on managers, clinicians

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 coordination 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 organsations, 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 coordination: professional partnerships (most general practices), networks (referral hubs, virtual wards) and hierarchies (NHS trusts, social services).

4.d Patients' experiences of continuities and discontinuities of care

4.d.i ***Sampling***

Since 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, hence who satisfied the following inclusion criteria:

1. 65 years old or more.
2. With complex healthcare needs, defined as having at least two of the following conditions: arthritis; heart failure; chronic obstructive pulmonary disorder; stroke; mental health problem (depression, dementia, psychosis, schizophrenia or bi-polar disorder); sensory deprivation (blind or deaf).
3. Receiving care for at least one year before the study from at least two provider organisations.
4. Living in own home or with family.

Exclusion criteria were:

1. Moderate or severe learning disability.
2. Receiving terminal care.
3. In criminal justice system.
4. Unable to give informed consent.
5. Too frail to give 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 pre-paid envelope supplied or, on occasions, by e-mail, phone or their GP surgery. Because we intended to characterise patients' experiences of the continuities and discontinues of care qualitatively, we interviewed small numbers of patients in depth until we approached data saturation (n=66; *Table 7*). Interviews typically lasted about 45 minutes and, given the patients' age and interest in the topic, often became somewhat discursive.

Table 7: English study sites – patient interviewees

Site	**Number**	**Age range ***	**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

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

The wide inclusion criteria meant 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, whilst the Sedgeton patients had all used services at the 'polyclinic', none of the Tarrow patients had used the virtual wards as many lived beyond their catchment area. Similarly, whilst 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

> **GP:** *very good at going and helping themselves* […] *well supported by helpful, intelligent and well-resourced families.* (F03)

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

4.d.ii ***Data collection***

Patient interviews were conducted using a semi-structured interview schedule (*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 spouse; and for one, his son) were present and contributed. We extracted data from the interview transcripts into a standard proforma (*Table* 8), a deductive coding frame.

Table 8: Data extraction template: Patient interviews

Main theme	Sub-theme: evidence for presence or absence of
Care Manager	Patient knows 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 coordination	Willingness to be own care coordinator 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

Free text answers were thematically coded by the researcher who had conducted the field interviews (initially using Nvivo) 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 8, 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 coordinate own care) and the coding of any ambiguous responses were agreed between the PI 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 healthcare and referral pathways across the last 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)

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 proforma (*Table 9*):

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.

Table 9: *Data extraction from general practice medical records*

Date	Condition	Transaction Type	Originator					Transfer type	Outcome	Recipient		CC’d	Comments
			Organisation	**Location**	**Dep’t**	**Role**	**Identifier**			**Organisation**	**Role**		

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, DNA notices or practice requests to make appointments for, for instance, chronic condition reviews, only the resulting encounter. These data describe the activity captured by general practice medical records (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, 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 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').

4.d.iii ***Initial qualitative analysis***

Our analytic framework (Section 2.c.i) listed observable features that would be evidence of continuity and coordination of care: the presence of a care coordinator and of a care plan; an ongoing relationship between care coordinator 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 coordination there, as collectively reported by its patients. We noted any differences between patients' accounts, any aspects of care coordination not anticipated in our original framework, and the broad (qualitative) patterns of care coordination reported in the patients' medical records. By comparing these case studies, we could then qualitatively compare study sites.

4.d.iv **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 SPSS Statistics v.21), declaring p≤0.05 as the significance level. (The findings chapters report which datasets 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 chi-squared, Fisher exact and ANOVA. This analysis contributed to answering RQ1 and RQ4.

4.e Cross-country comparison

4.e.i ***Design***

Given our research questions, the ideal comparator against which to compare care coordination by care networks would have been a single, integrated organisation providing primary medical care, community health services, 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 coordination mechanisms available in these two settings would contribute to answering our research questions RQ1, RQ2 and RQ4. 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, asthma). We did not analyse patient records, but did interview a small number of patients (not reported here).

4.e.ii ***Sampling***

Using the researchers’ own knowledge and networks to identify study sides, we selected the following primary healthcare centres (PHCC: polyclinic) 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 Stockholm county council (SLL). SLL directly line-managed the three under heading (1) above and commissioned the others through contracts. In size and function they were similar to the larger among NHS general practices.

4.e.iii ***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 Stockholm county council (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 coordinated 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, 2011) replicated a US survey to discover the use of recommended care coordination practices and of information technology for coordination in primary care.[252–254] The response rate was 37%, with a bias towards the larger centres. Whether there was a higher proportion of public compared to private PHCCs replying is unknown, as there are no reliable national data about PHCC ownership.

4.e.iv ***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.

4.f Data synthesis

In all, we assembled the data summarised in *Table 10.*

Table 10: Data assembly

	Interviews	Other material
Patients	66	64 medical records
English organisational case studies	80	160 documents and press reports
Sweden	40	2 surveys of polyclinic heads
Secondary data	N/A	760 published papers and research reports

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.

4.f.i ***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’ experience of the observable features of continuity and coordination of care (see *Section 2.c.i)*.
2. Next we compared the pattern of patient experiences at each site with the initial analysis of care coordination 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 whilst 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 causes[255] such as patients' own resources and decisions. However, our health worker informants more often reported care coordination mechanisms, or their absence, not mentioned in the patient experience data. (For example, 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 studies 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 upon 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.

4.f.ii ***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 coordination 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 sites where:

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

In this way we addressed RQ1 and RQ3. By comparing these findings with our original analytic framework and hypotheses, we also began to address RQ4. We furthermore systematically compared the corporate general practice (Fivecastles) against the professional partnership general practices in the other four sites, thereby addressing RQ2.

4.f.iii ***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.

4.f.iv ***Inducting patterns of managerial discretion***

Given our research questions, 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 RQ3 and RQ5.

4.g Ethics and research governance

Ethical approval was obtained for the study from the NHS REC 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.

FINDINGS

5 Patients' Experience of Care Coordination

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%) in private housing. On average, patients reported four chronic health problems, most commonly heart disease, arthritis, diabetes and gastroenterological conditions (table 7). Patients tended not to mention problems such as impaired mobility or falls but these were apparent from, for example, their activities of daily living (ADLs) and health appointments. For many, such problems were increasing. 62% 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 ADLs, 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'. 81% 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' experience of care coordination, 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.

5.a 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 (OOH, ambulance, ED) as unavoidable proxies when their GP was unavailable.

> **Patient: '*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.' (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 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, bloods), although this figure was inflated by one patient who had 136 encounters for wound care. Other important encounter types directly involving patients were phone calls between surgery and patient (14%) and home visits (6%). 43% were reviews in the absence of the patient. The remainder were largely the receipt of information from other organisations. 27% of all records reported external reviews or treatment of the patient, 7% other information from other care providers and 3% discharge summaries. About 20% of the recorded patient contacts originated from secondary care teams and 14% 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 OTs). Only one encounter originated from a care agency and none from social services.

5.a.i ***A care coordinator 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 coordinators. One rested on the criterion that the care coordinator is the person who initiates care (e.g. makes a referral). On this basis care coordination was taking place in 12% of encounters and a care coordinator was identifiable (in at least some encounters) for most (89% of) patients. GPs most often assumed the role (64% 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. By this criterion there were a mean of 2.7 care coordinators per patient (range 0-10). The two common scenarios were of patients whose GP was their main care coordinator (38%) and those whom had no main care coordinator (i.e. no one individual responsible for the most referrals). One of the Whinshire general practices showed no evidence whatever 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 coordinator is as someone who does more than just initiate care. For example she seeks information, raises queries, acts as an advocate, chases up treatment and delegates tasks; or the patient seeks them out rather than other sources of care. By this criterion about 11% of patients' encounters involved care coordination. 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 main care co-ordinator for 53% of patients, 28% had no identifiable care co-ordinator, and secondary care was the only other substantial source of care coordination (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 on either definition. Most (66%) experienced care co-ordination of both forms. Consequently a patient's care was typically being coordinated 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 coordination as such as valuable, but having one's own GP was appreciated as other studies

[106106] have found (see 5.a.ii5.a.ii). In each site a majority of patients felt it important to have someone responsible for coordinating 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:

> **Patient:** *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.* (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 this was why his diabetes had remained undiagnosed for a long time:

> **Patient:** *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.'* (W38)

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

> **Patient:** *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.* (S54)

Patients seldom identified a case manager nurse as their care coordinator, 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.

So 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:

> **Patient:** *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.* (T057)

5.a.ii ***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.

> **Patient:** *Yeah, I go usually three times a year, about every four months and then you see one of the team* […] *it’s nearly always a different person.* (S55)

Medical records showed that patients on average (mode) saw 4 GPs in the preceding year (range 1–10). Patients divided almost equally between the 55% who saw the same GP at more than half their encounters at the practice, 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 healthcare 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 both the former had a usual GP compared to 27% in the latter).

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

> **Patient:** *[S]urely one doctor has got more interest in you than any Tom, Dick and Harry, as you might say.* (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 16/23 GP encounters (70%), despite the GP only working part-time. There were two systematic exceptions. Some patients focused not on whether they knew the GP but whether the GPs knew them:

> **Patient:** *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.* (E03)

The other was that when patients felt that they had an urgent problem (e.g. an exacerbation), they wanted swift access and were willing to

> **Patient:** *take a chance on who you're getting.* (S55)

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

> **Patient:** *I have to say they were all absolutely gorgeous but there was no continuity. I saw a different person every time I went.* (E05)

Telephone and e-mail were also partly replacing face-to-face contact. In the records we studied, phone 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 the GP for advice on that problem:

> **Patient:** *No, because I thought if it's arthritic that's who I want to see, I want to see* [consultant]. (W36)

Access was direct, they felt *'able to query things'* and *'just pick up the phone'*. Then they only went

> **Patient:** *to see the GP for small ailments, the other ones I can go straight to the hospital.* (W40)

However the medical records did not corroborate this pattern.

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

5.a.iii ***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:

> **Patient:** *I would rather just have the care, you know. Never mind about the plan.* (S45)

Since 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:

> **Patient:** *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?* (S55)

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

> **Patient:** *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.* (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:

> **Patient:** *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 coordinate all these things* […] *It may be that* [GP] *does know these things, but I'm not aware that he does.* (T068)

From our study general practices, 51% of GP referrals were to secondary care, and only 34% into 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:

> **Patient:** *should mean at least one visit from somebody in the practice, if not a doctor then certainly a practice nurse.* (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:

> **Patient:** *Oh yes, I think they have to, I think isn't it about six weeks; I believe that's what it is* (S49)

and less common immobilising illnesses where no such support was offered. Some patients therefore had quite a positive experience of post-discharge care:

> **Patient:** *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.* (E011)

The experience could also be positive for home assessments to inspect beds, flooring, need for equipment or catheters. In these cases the hospital clearly had triggered help in the community.

5.a.iv ***Reviews of the patient's circumstances: Flexible continuity***

About a 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:

> **Patient:** *I suppose the longest between interviews would be about two 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.* (E04)

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

> **Patient:** *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.* (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 and carried out by practice nurses, and seemed superficial to some patients due 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:

> **Patient:** *they 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.* (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, not 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.

5.a.v ***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 studies

[106106]), so that the patient felt:

> **Patient:** *akin to being on a conveyor belt* (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:

> **Patient:** [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.* (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:

> **Patient:** *First of all, they never pick the phone up; secondly, I think they make more effort to look if you're there.* (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 community health services varied significantly between sites. Only 33% of patients in Fivecastles had any such input (and levels in Whinshire were also below the sample average) whilst 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. A patient in his 90s 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, could struggle into the surgery by taking a taxi to the bus stop.

5.a.vi ***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 information being missing (3%), e.g. '*there are no notes available to me*' (E10). Between a quarter and a 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 DGH had not acted on an urgent GP referral, the patient was admitted as an emergency two days later, partly because:

> **Patient:** *the protocol for handling things like fax hadn't really been established* (F17)

and because of individual errors, for instance a medical secretary:

> **Patient:** *hadn't appreciated that it was urgent, or that she had some role in making urgent appointments* (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:

> **Patient:** *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?* (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 a 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.

5.a.vii ***Patient contributes 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 between 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.

41% 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 variously lacked knowledge 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 speciality. A friend had advised one patient to

> **Patient:** *learn as much as you can about your own illness – as you will encounter doctors and nurses who don't.* (W32)

Not all these patients were happy coordinating their own care:

> **Patient:** *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.* (W38)

These individual responses seemed partly to reflect personality:

> **Patient:** *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.* (F20)

However, they might also reflect the patient's state of health. On occasion patients found difficulty in filling their assigned roles, recalling information for example or accessing counselling. One patient tried referring himself to CRUSE, but was put off by the condition of others seeking help and asked himself:

> **Patient:** *'Do I want to go in here?' I thought, 'No.' .... so I left it.* (S48)

The responses also reflected a lack of available or known options, as with the patient without family and using two crutches who while in hospital following a fall organised a removal company to facilitate discharge:

> **Patient:** *and 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.* (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. Yet comparing their interviews with their medical records, patients tended if anything to under-estimate their health problems.

Patients at all sites depended on their spouses, other family members or wider social networks to provide additional care:

> **Patient:** *good friends bless them* (E02)

and help them access health services. Levels of informal support varied considerably. Many patients thought that they should not be over-demanding:

> **Patient:** *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.* (W42)

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

5.b 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.

5.b.i ***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 other first responders.

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

> **Patient:** *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.* (F20)

Patients explained:

> **Patient:** [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 one day a week.* (F15)

> **Patient:** *They run their practices very much more as a business than they used to* […] *they certainly don't want to over-staff the practice with more doctors than necessary, so obviously it becomes a little bit more difficult to get an appointment.* (F24)

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

Concomitantly, while 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

> **Patient:** *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.* (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 and it 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 mentioned the idea of bypassing general practice for care reviews or queries, mentioning only standard recalls for urology and cardiology, for example, while in Eastmere and Whinshire patients maintained direct contact with the hospital in the event of exacerbations:

> **Patient:** *Well* [the heart specialist] *told me to ring there, his office, if I get serious problems.* (W40)

5.b.ii ***Different experiences of inter-organisational coordination***

Patients' experiences of transfers to other providers appeared to differ in two ways in Fivecastles from the other study general practices. Fivecastles patients engaged mostly with the general practice or hospital, not so much 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 practice's willingness to refer them as private-payer patients to private healthcare providers. The Fivecastles general practice readily did so. Several patients had GP referrals for private treatments at the DGH, local and London private hospitals, especially for cardiology and conditions such as a brain cyst where rapid treatment seemed important. Even a patient in social housing 'went private' when NHS providers were slow to diagnose a twisted gut. The Sedgeton general practices did not facilitate such referrals:

> **Patient:** *if I haven't 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.'* (S45)

Neither 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.

5.b.iii ***Different experiences of 'second-responder' care coordination***

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:

> **Patient:** *they 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.* (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:

> **Patient:** *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.* (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 coordinator.
2. Few patients had designated care coordinators.
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:
    (a) Lower perceived relational continuity with the GPs.
    (b) Fewer home visits, especially compared with Eastmere.
    (c) Less engagement with community health services, especially compared with Sedgeton.
2. Higher use of private providers in Fivecastles.
3. Care coordination 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

6 Care Coordination in General Practice

6.a Explaining patients' experience at general practice level

Next we consider which coordination 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 how far the latter may explain the former.

6.b Commonalities across the general practices

6.b.i ***Care coordinator***

The patients we interviewed usually felt that they knew where to seek additional healthcare and it was from a GP; preferably their 'usual' GP. Few of them, though, were aware of having a designated care coordinator, an impression that their medical records confirmed. Nevertheless, GPs in our study practice believed that being a care coordinator was both the proper, normal role for a GP:

> **GP:** *You are always a case manager for the patient you are seeing at any one time.* (WP01)

and that GPs were best qualified for it:

> **GP:** *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.* (WP01)

Frequently their coordinator role was tacit rather than openly discussed. GPs would be care coordinator by default when patients did not fit neatly into any other category with special care coordination arrangements.

For particular classes of patients, having a named GP with specific care coordination 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 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, either 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, 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 GMS contract. Practices did not always have the option to provide GP cover for community hospitals (as in Eastmere). While GPs valued their care coordinator role, they were content to delegate some of it to, for example, community matrons, ANPs or other external care coordinators (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.

6.b.ii ***Care plans***

One reason why care plans were not very visible to patients (*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 coordination role, nursing and care home residents were something of an exception. In Tarrow and 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 QOF register in two general practices and

> **GP:** *every* [...] *nursing home and residential home bed* [...] *mainly around end of life care and anticipatory care plans as well as medication reviews.* (EP19)

There, and in Tarrow, these patients would get a care plan within one 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.

56% of our patient sample were aware of having their care reviewed regularly (if infrequently, for some). For those for which this happened, our general practice informants told us that care reviews were made either by recall, by 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 multidisciplinary team (MDT) meeting. GPs' review and recall processes (e.g. medication reviews) were largely driven by QOF targets:

> **Community team lead**: *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* (SP06)

or more guardedly:

> **GP:** *There are some useful things about QOF – it does flag things to be done – but some are utterly meaningless.* (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, diabetes). These were the care reviews that some patients found 'superficial', not counting them 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 (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 multi-agency (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 white-list 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:

> **GP:** *Because obviously patients don't tend to be kept on for out-patient 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 weren't being followed up as well as they should have been. So those sorts of processes can be quite useful*. (P03)

Partly this was driven by QOF and the CCG's emphasis on audit, but some were

> **GP:** *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.* (FP03)

Our patient interviewees, though, 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 since GPs thought care planning was laborious and of limited utility (see above), the same applied to formal care reviews (a corollary of care planning).

6.b.iii ***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. An immediate explanation was heavy and increasing GP workloads. Care coordination of older people with complex needs was only one – 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 ten 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.

> **GP:** *[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.* (EP19)

> **GP:** *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.* (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 coordinating 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; see below).

6. In Eastmere and Fivecastles, both patients and health workers described receptionists as barriers to patient, even ANP, access to the GPs.

The study general practices' additions of new services and specialisations reflected the GPs' personal background and interests. Thus both 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, ECGs, 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 created more work, because if a specialised GP was present the other GPs tended to use them. Similarly, the GPs felt that a nurse practitioner 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 nurse practitioners, practice nurses, health care assistants and phlebotomists. The small corporate general practice had the least support staff; a part-time phlebomist and the practice nurse, but also a pharmacist who conducted medication reviews, something unusual in a non-dispensing practice and effectively delegating responsibility for signing off scripts. Because the pharmacist:

> **GP:** *knows a lot of the patients from being behind the counter at the chemist* (FP03)

this arrangement was also:

> **GP:** *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.* (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:

> **GP:** *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.* (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.

> **GP:** *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.* (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.

6.b.iv ***Internal care coordination***

Over one fifth of our sampled patients felt unable to assess whether the people looking after them worked well as a team, but most of those responding (77%) thought that coordination ('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.[20] This study included instances of both arrangements.

The GPs held practice-level ‘team’ meetings to deal inter alia with care coordination 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) besides ad hoc informal discussions, often daily:

> **GP:** *we 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.* (WP01)

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

> **GP:** *we 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.* (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, inter-organisational primary care teams (see *Chapter 8*).

GPs in the study general practices made efforts to share information (besides 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, 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. Yet to varying extents, general practice information systems were also administratively closed to, and technically not inter-operable with, other providers' or care networks' health records systems. The data available to the Eastmere CCG was reported as being '*extremely poor*' (EP19). Partly this closure may have been because GPs anticipated, or had already experienced, that having too much information about a patient:

> **GP:** *clogs up the record and leaves us* [GPs] *to cut the wheat from the chaff.* (WP02)

This GP found the task of spotting the important action points too slow as a consequence, which might raise risk management issues. Nevertheless, general practice information systems were gradually becoming more accessible to external healthcare providers (see *Chapter 8*).

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:

> **GP:** *Oh, my dream ... I would love us to hire our own district nurse, health visitor, mental health nurse.* (EP19)

Referral to additional providers, and the ensuing care coordination, 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 7) the consultant retained responsibility for patients.

6.c Differences in care coordination across the study general practices

6.c.i ***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 coordinating 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 5*) 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 coordinate 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 an 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 to 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 the latter reflected its corporate ownership, small size or normal referral patterns in that CCG. In addition, the corporate study practice had a white-list of patients who were allowed easy access to the GP:

> **GP:** *if 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 don't like bothering the doctor but, you know, are quietly sitting at home and not doing very well.* (FP03)

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

6.c.ii ***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 (see *Chapter 8*), could be used to highlight patients whose needs or service use were increasing. They planned to give the OOH 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.

6.c.iii ***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.[18] In Eastmere, OOH 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 coordinating bodies ('hubs') in Eastmere and Sedgeton also accepted self-referrals, but since their main role was care network coordination (routing or diverting referrals originating from other provider organisations), we describe them in *Chapter 8*.

6.d Comparison of patient experiences with care coordination mechanisms in general practices

To the extent reported above, the care coordination 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.

6.d.i ***Organisation-level coordination structures invisible to the patient***

Some coordination mechanisms were, for patients, behind the scenes. Patients might notice its effects, but not the coordination mechanism itself. Thus some case conferences (or equivalents) and care reviews involved only general practice staff, not the patients, who were not always aware that they were taking place. Patients knew that non-doctors at the practice provided, even coordinated, 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 co-located (e.g. mental health support) services that some of the study general practices provided.

6.d.ii ***Non-organisational influences on care coordination***

Some aspects of patient experience of care coordination had obviously non-organisational explanations: patients liking to have their ‘own’ GP; whether patients took the initiative in coordinating 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 background and interests also influenced how care was coordinated and what resources were available for it.

6.d.iii ***Higher-level constraints on care coordination***

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' coordination of patients' care were as follows:

1. Availability of budgets or payments for additional care coordination work.
2. The presence and scope of multi-agency 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 coordination 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, coordinating complex care. Yet 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.

7 'Second-Responder' Providers: Organisation-Level Care Coordination

7.a Explaining patients' experience of 'second-responder' providers

To care for patients with complex care needs, general practices had 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 where 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 coordinated care provision internally, and how far their coordination 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 coordinators 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 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 coordinated within than between services.
8. CHS, especially district nursing, support 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.

7.b Second-responder organisations: Care coordination commonalities

7.b.i ***Care coordinator***

Only one of our patient interviewees considered that they had a nurse as their care coordinator. All the study site CHS identified case managers for patients with complex, long-term conditions, but which patients had one, the criteria for having one and arrangements for assigning that role varied considerably across study sites and between services. To illustrate the complexity, in Eastmere, patients with two or more unplanned admissions in the last year and taking four or more medications could be assigned a CHS care coordinator. In Whinshire, post-acute patients were covered, each ANP covering (as in Eastmere) a number of designated general practices. In Sedgeton, patients referred to a short-term CHS service (intermediate care, IV community therapy, community rapid response) were variously allocated a clinician to assess them, then transfer them to the necessary professionals. Outside the virtual wards (see below), 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 coordinator. One virtual ward scheme uncovered high levels of unmet need, with some complex housebound patients only seeing a district nurse:

> **Nurse:** *we'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.* (TP10)

Usually the coordinator was an advanced nurse practitioner or equivalent (e.g. community matron). In Sedgeton, each discipline had a professional responsible for each client, so

> **Clinical Services Manager:** *a therapist who is allocated a case will stay with that client right the way through their journey whilst they're with us.* (SP07)

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

> **Physiotherapist:** *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.* (F08)

Health workers' propensity to take on the care coordinator 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 coordinator.

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) tended to act as assessor and care coordinator, and to make onward referrals. In Tarrow, the community mental health team usually acted as care coordinator, 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.

7.b.ii ***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, say, what oxygen level was normal for a patient, which aided timely discharge by showing when the patient's condition had re-stabilised 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.

Since 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 co-location 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

> **Geriatrician:** *in a crisis it takes a good carer or relative to recognise the need to bring any of the individual care plans into hospital.* (SP15)

Patient involvement in the care planning process was also often limited, particularly if mental health workers were involved, because we are:

> **Team Facilitator:** *talking about very vulnerable individuals by this stage.* (TP04)

National guidance recommended the Care Programme Approach for planning complex mental healthcare, 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 six-week re-ablement programme.

7.b.iii ***Care review***

About half 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, other patients when they came to a clinic. In Fivecastles, patient reviews were being formalised into 'visit standards':

> **Locality Manager:** *so if the patient's seen daily in a seven-day period, at least one visit is undertaken by a qualified practitioner.* (FP04)

Review frequency reflected individual need:

> **Physiotherapist:** *I mean sometimes I'll review somebody monthly, sometimes it's weekly, basically our role is teaching a patient to manage themselves.* (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 six-month checks that NICE recommended for patients with heart failure. Our informant was unsure whether those checks actually happened.

In contrast, review was normal for re-ablement patients (commonly on six-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 they needed ongoing care.

Review was also integral to mental healthcare. The Eastmere community mental health service reported that they aimed for three- or six-monthly care plan reviews depending on status, but would review weekly during crises, and daily if patients' medication or behaviour warranted, updating

> **CPN:** *their risk assessment/care plan, every other day, every week, because it needs to be up to date.* (EP13)

They also reviewed dementia patients six-monthly rather than yearly (as in NICE guidelines).

7.b.iv ***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 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:

> **Nurse:** *I think there's a delay across most services to be honest in that everybody's* [community, secondary, social care] *under the same pressures.* (TP05)

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

> **Nurse:** *I am the only person at the moment, for the matrons, who's got health assessment and who can prescribe.* (TP10)

The CHS heart failure service at Sedgeton was two-thirds under strength, relying heavily on the healthcare assistants as '*sort of care coordinators*'. Such shortages directly affected longitudinal continuity of care because

> **Speech therapist:** *there's a memory for the person who deals with that particular area of care that obviously improves outcomes for the patient*. (SP01)

OTs 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 two 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, 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, hence they cost more to employ, which had to be weighed against any savings resulting from higher productivity:

> **Nurse:** *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.* (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 six-monthly reviews of dementia patients' care to an HCA). Such delegation could have unforeseen advantages in that more regular contact generated trust and helped reveal patients' needs:

> **CPN:** *once you get to speak to a carer there's often other things going on.* (EP14)

Similarly in Whinshire CHS, the caseload was stratified from low- to high-complexity patients, with DN work increasingly concentrated on complex patients. In some DN teams, the HCAs 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 re-admission.

7.b.v ***Coordination 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 desire for '*seamless*' CHS (enabling, say, district nurses to work more closely with community matrons) another.

Even under single management, working practices were often limited to a single occupational 'silo', not standardised or coordinated 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 this variation occurred within one manager's span of control. Information management was often equally disparate. In Eastmere:

> **Team Facilitator:** *we have cardiac, we have respiratory, all using different paperwork, diabetes, different paperwork, Parkinson's.* (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 having a DN visit).

In all study sites, providers used 'horizontal' multidisciplinary teams 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

> **Team Facilitator:** *they were A & E nurses and had it tattooed on them.* (EP07)

Another area had a history of non-cooperation between equipment and learning disability OTs. In Sedgeton:

> **Speech Therapist:** *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.* (SP01)

Then the word 'team' was little more than a euphemism for a hierarchical, uni-professional 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, OT):

> **Nurse:** *So unless a patient has COPD then the OT in the respiratory 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.* (SP04)

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

7.b.vi ***Vertical integration***

Second-responder providers substituted primary for hospital care by 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 coordinating bodies (see *Chapter 8*).

Mental health services were vertically integrated, with consultants working in both community and in-patient 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 coordination. 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.

7.c Wider organisational integration

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

7.c.i ***CHS 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.

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

> **Therapist:** *no 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.* (FP14)

Perhaps unwittingly, this regime resembled the Netherlands *Buurtzorg* system[257] of giving community health workers high levels of autonomy and responsibility. Transfer-of-care coordinators worked in the ED assessment unit to divert patients and avoid admissions:

> **Locality Manager:** *Somebody else had fallen, okay 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.* (FP04)

Even within the trust, lack of communication could sometimes frustrate continuity of care. CHS were not always informed when their patients returned to hospital and the care of patients who missed OPD appointments, even due to 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 coordinators provided an ED 'front-door' referral diversion service. Specialist nurses had become hospital based but

> **Locality Manager:** *they're still very accessible to us* (F04)

and would visit patients with the community nurses when required.

The local hospice-at-home was officially an external provider, but:

> **Locality Manager:** *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.* (F04)

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

7.c.ii ***CHS 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 healthcare was integrated through inter-disciplinary teams. The community elderly care team included geriatricians, psycho-geriatricians, CPNs, OTs and nurses. The DN team lead's role was also to better integrate physical with mental healthcare, 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. Yet 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

> **Nurse:** *just work very differently* [to us in CHS]*, even though we're all in the same organisation.* (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 the working day:

> **Nurse:** *if 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).* (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.

7.c.iii ***CHS 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:

> **Manager:** [D]*elayed transfers of care were eradicated within six week*s

moving the trust from being

> **Manager:** *about the worst in the SHA to the best*

and this where there was

> **Manager:** *a high performing acute sector and* […] *an under-invested in community sector.* (TP01)

Expenditure had to be shifted so that there were no overall savings:

> **Manager:** *So in a place like* [county]*, high performing and quite small, the benefits are clinical and quality, clinical quality, not economic.* (TP01)

The subsequent experience of organisational disintegration revealed, with hindsight, how much easier organisational integration had made it to coordinate and maintain longitudinal continuity of care:

> **Nurse Manager:** *we learnt so much about each other, adult social care and health, because we were together for several years.* […] *We weren't given the five years to really make it embed into practice* […] *it's such a great shame.* (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. (*Chapter 8* describes a second, separate 'virtual ward' that GPs ran.) It was consultant run and staffed mainly by nurses and community matrons:

> **Nurse Manager:** *assertive, highly skilled nurses who are well versed at risk assessment* (TP06)

who work largely in the acute hospital, identifying in the ED, clinical assessment unit and ward rounds patients who could be cared for at home. On discharge:

> **Nurse Manager:** *the 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.* (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 ALoS, rather than entirely substituting primary for in-patient care. The team of consultants, community matrons (who could prescribe), nurse practitioners 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.

7.d Patient experiences and care coordination within second-responder providers

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

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

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

7.e Higher-level constraints on care coordination

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 inter-professional demarcations and rivalries, staff shortages and the re-separation of services under financial pressure. More immediate inter-organisational constraints on care coordination at second-responder level were:

1. Which services were not internally available: in-patient, mental health or social care services depending on the case, and always primary medical care.
2. The presence and scope (or absence) of multi-agency care teams.
3. Closure or non-inter-operability of other providers' information systems.
4. Delayed transfers due to capacity bottlenecks in the next provider(s) along the care pathway.

This and the previous chapter show how care coordination 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. Multi-agency teams to provide patients with access to those services
3. External providers willing to co-locate 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 coordination work.

Patients had a greater proportion of ongoing contacts with hospitals in Fivecastles and Whinshire but lower levels of engagement with community health services. 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 district general hospitals serving its patients.

Often one provider (e.g. CHS) also hosted a care network coordinating body (e.g. a referral hub). The same person or group that coordinated care *within* that organisation might also coordinate *between* providers. We next report how the care networks achieved that.

8 Transitions between Providers: Continuity, Care Coordination 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 coordination 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 coordination.

8.a The consultation model

The archetypal consultation model of care coordination (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:

> **GP:** *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 twenty-four hour sitter in the property for three 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.* (SP10)

Here, the ability to co-ordinate care effectively was explicitly facilitated by a meeting of the Integrated Primary Care Team (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:

> **Voluntary Organisation Organiser:** *they did not need to tell us what to do – just tell us there's an issue.* (SP08)

Certain inter-organisational referrals still had to be made via the GP. Hospital dischargees 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 trivially (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 advanced nurse practitioners (ANPs) to their mental health counterparts went via the GP even when ANP and CPN were in the same organisation). The amalgamation of organisations reduced the proportion of inter-organisational patient transfers that had to be made via the GP, while organisational separation or the transfer of staff (e.g. physiotherapists, in Whinshire) to another organisation increased them.

8.b 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:

> **Nurse:** *I think a lot of it depends on each individual ANP, do they know what's out there, not everybody necessarily does.* (TP03)

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

> **GP:** *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.* (FP03)

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

8.b.i ***Inter-organisational 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, due 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:

   > **Nurse:** *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.* (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, 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:

   > **Manager:** *some days it will work; other days it won't.* (EP18)

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

8.b.ii ***Co-location***

To varying extents, all the study sites had replaced co-location 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 co-locating *individual* staff members. In Eastmere, for example, primary care dementia practitioners employed by the hospital trust were co-located 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:

> **Manager:** *people were coming to our attention six 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.* (WP08)

Given time for trust and good working relationships to form, the benefits of co-location 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):

> **Manager:** *you can walk up and down, you can discuss easier face-to-face.* (EP06)

The Fivecastles general practice noticed the value of co-location once it ceased:

> **GP:** *[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.* (FP03)

The experience was similar in relation to co-locating the memory service and intermediate care team:

> **Team Facilitator:** *it makes for easy referrals doesn't it? And you're on hand and you can deal with things quite quickly.* (TP04)

Pharmacists were in some areas also co-located with general practices and undertook patient reviews.

Co-location 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 co-location sufficient to stimulate communication between staff, even in the same organisation, if they were simply personally uncommunicative. At Sedgeton, some hospital out-patients, CHS and mental health services were co-located 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 this co-location 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. Co-located 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.

8.c Managing care coordination through care networks

In all five study sites, formally managed care networks had been established, the better to coordinate care across organisational boundaries. Earlier informal inter-organisational 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 coordination by developing new models of long-term condition management to help patients 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 coordination.

8.c.i ***Inter-organisational 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 six weeks for most post-discharge patients). Networks established a single entry point for referrals, with swift, formalised assessment and triage for most patients, 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 inter-organisational care network did this in Fivecastles.)

Only certain patients had cross-organisational care plans (*Chapter 5*), but it was usually those whose care was coordinated by a network. Whinshire, for example, had developed an integrated electronic health record 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 multidisciplinary team 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 (though 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

> **Manager:** *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.* (FP09)

8.c.ii ***Network coordinating body***

Care network coordinating bodies went under various names: 'referral hub', 'assessment service', 'emergency intervention service' 'proactive care', 'virtual ward'. In our study sites, either CHS hosted the coordinating body or the providers with the largest or most problematic interfaces jointly did so (Eastmere, Whinshire). In some sites the network coordinating 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.

8.c.iii **Care coordinators**

Care networks had also assumed care coordination responsibilities to various degrees, sometimes coordinating their patients' care themselves, but sometimes assigning it to an existing service. The networks usually coordinated care through a combination of case manager and inter-organisational multidisciplinary team.

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 which patients were eligible for case management, although nowhere were all patients eligible. In Eastmere, the '*grey area*' of patients who seemed still to lack a care coordinator caused staff a lot of stress. However, some patients had no designated care coordinator because (we were told) their needs might be too complex, high level and unstable; responsibility for care had to remain flexible.

Care coordination by case management was, in our study sites, a hybrid arrangement, transitional between the consultation model and care coordination by teams. It was consistent with the consultation model principle in that the GP might delegate tasks – here, care coordination – to others; and in that the new case manager replaced the GP at the hub of a 'star-pattern' configuration of referral links. Yet in doing so it also partly transferred the captant role. (In some places, though 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:

> **Manager:** *before, 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.* (WP16)

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

The care coordinator role might shift between case manager and multi-agency team:

> **Nurse**: *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.* (WP03).

A patient in Sedgeton might first be assessed by, say, a neurology team, 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 coordinator.

Although patients might have a named care coordinator, much of the actual coordination work was undertaken by **inter-organisational, multidisciplinary primary care teams**. Referrals between CHS and social care were often decided by case conferences and reviews. The nomenclature ('multi-agency 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 (for instance, 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:

> **Nurse:** *you'll get whoever's available on the day, so you may end up with three, you may end up with six, eight.* (TP10)

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

> **Nurse:** *hopefully 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.* (TP10)

Indeed, multi-agency care networks undertook most of the multidisciplinary team 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).

8.c.iv ***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, while 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 specialist

[182182]). GPs were at times conservative about referring to new services, fearing that they would lose control over quality of care (Fivecastles, 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 arms-length trading company had assumed the county council's reablement and care functions. Social services in Fivecastles had a programme coordinating 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 under-developed or under-valued, 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 and community health services 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 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

> **Manager:** *not knowing properly where we can, what we can access, when we can access it and how we do that.* (EP20)

Seeing the care network's referral rules as a cause of delay, they 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 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, 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:

> **Manager:** *everybody refers, should refer to everybody else in the community and that's what makes the community.* (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 CMHT 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, hence in which inter-organisational boundaries remained:

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

Yet these different configurations of inter-organisational boundaries made little difference to what care coordination mechanisms existed and how they were used across the remaining interfaces.

8.d Remaining interfaces

The main practical purpose, and to varying extents effect, of the care networks was to minimise inter-organisational barriers to continuity of access. Yet in all 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. It 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 inter-organisational 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 inter-organisational care coordination bodies alongside the GPs' coordinating 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:

> **Voluntary Organisation Organiser:** *we looked at a hundred people who'd been referred into Adult Social Care but were waiting for an assessment. Twenty-four percent of people had passed away before they got their Personal Budget and seventeen percent of people had to go into residential care* (TP08)

and were irrelevant to quality of care:

> **Voluntary Organisation Organiser:** *they've had that thirty-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 don't have that 'good life' discussion; they don't have that person-centred discussion.* (TP08)

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

4. *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 for example in OT (Whinshire, Tarrow); befriending services (Sedgeton, Whinshire); 'low-level' psychotherapy (Whinshire, Sedgeton); day care (Eastmere, Tarrow, Fivecastles, with funding being withdrawn in Whinshire); NHS-funded nursing home beds (Sedgeton, Eastmere, Tarrow); care agencies (Eastmere, Tarrow); local rehabilitation services (e.g. cardiac rehabilitation programmes in Eastmere, 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:

> **Clinical Facilitator:** *if somebody has to travel to* [hospital] *every day just to have their INR and their clexane done because they've had a PE or a DVT, I could do that at home.* (EP07)

5. *Weak or missing inter-organisational links*, for instance between the CHS and parts of the mental health trusts (Fivecastles, 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.

6. *Mismatched financial incentives and managerial targets* between provider organisations adjacent on the care pathway: for instance QOF vs tariff (PBR) payments rather than whole-pathway payments; and targets formulated in terms of speed of throughput rather than continuity of care.

7. *Organisational separation often meant separate location* of services and their staff. Co-location projects were a workaround.

8. *New organisational boundaries* exacerbated the above problems. In Tarrow, the reversion to separate health and social care providers meant that:

> **Nurse Manager:** *there are single points of referrals* [in an integrated organisation], *now we've got two, you know, it's just got more complicated and I struggle to see how it's become more cost effective.* (TP06)

In mental health services:

> **Team Facilitator:** *what would enhance it* [longitudinal continuity of care] *is a rapid funding panel process because sometimes we perhaps have done our bit and we're left holding on to someone unnecessarily because of the protracted funding.* (TP04)

These barriers to care coordination were unevenly distributed across the inter-organisational boundaries in the care networks that we studied:

1. Between general practices and NHS trusts, all the above barriers were observed.
2. Between NHS providers (both general practices and trusts) and social services, barriers 2, 3, 4 and in some study sites 6 were present.
3. Between acute and CHS trusts we found barriers 1, 2 and 4.
4. Between CHS and mental health services we found barriers 1, 2 and 3, and in Eastmere and Sedgeton barrier 5.

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.

8.e Care networks' dependences on health system governance

Certain NHS-wide governance structures and higher-level NHS management both enabled and constrained the networks' care coordination work. 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 six-week time limit patients had to be financially assessed before receiving ongoing social care.
5. 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:

1. Establishing care networks and obtaining providers' participation therein.
2. Adoption of inter-organisational care processes, hence reducing the number and increasing the match of inter-organisational interfaces.
3. Closed, non-interoperable provider information systems with inconsistent clinical coding and lacking risk assessment data.
4. Adoption of inter-organisational care plans and health passports.
5. Pooled budgets.
6. Capacity imbalances between providers.
7. Service location.
8. Mechanisms for capturing evidence of patient experience for use in designing care coordination.

9 Care Coordination and Health System Governance

CCGs and Health and Well-Being Boards (H&WBB) were responsible for the horizontal and vertical coordination 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 coordination, and hence to continuity of care.

9.a Managerial discretion at care network level

9.a.i ***Creating care networks: Obtaining provider participation***

In all study sites, the PCT, or later CCG, had either established new care networks (Fivecastles, Tarrow) or adopted and formalised one initiated by another organisation (Eastmere, Sedgeton, Whinshire). The same applied to case management schemes. *Table 4* in *Chapter 4* 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:

> **Voluntary Organisation Director:** *see the interests of all the partners and seek to identify solutions that yet didn't run against the interests of all the partners* (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 (see *Chapter 7*) became institutionalised. After the pilot collaboration with the county council ended in Whinshire, it became:

> **Social Care Manager:** *impossible to keep track of the different boards and sub-groups* [...] *the same people are sitting in four different meetings* […] *no one knows which meeting actually has the delegated authority to decide anything.* (WP17)

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

> **Social Care Manager:** *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?'.* (WP17)

For instance, the care coordination 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 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 our study site CCGs encouraged voluntary bodies that provide additional services and participate in care coordination work.

The CCGs also mandated, and in some instances designed, the cross-organisational care pathways that the care networks operated. Whinshire CCG constructed two re-ablement/recovery pathways for older people with mental health problems (e.g. dementia) to 'step down' into bedded care either at an NHS sub-acute 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:

> **Manager:** *to be much more responsible for a coordinated way for, particularly, people with complex needs.* (SP09)

Sedgeton CCG funded two ‘interface geriatricians’ to coordinate 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 the providers and health workers involved. The example of Eastmere shows that achieving all 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, even a cause of disagreements.

Commissioning played little direct part in the care coordination mechanisms that we observed. At the time of this study CCGs did not commission most general practices, but all the study site CCGs used discretionary Directly Enhanced Services (DES) 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 inter-organisational care coordination. For hospitals they rewarded activity rather than its prevention, and were an incentive to retain caseload and services.[56] 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:

> **GP:** *a lot of them just took the hit and took a fine.* (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 report 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 are not accidental victims of the personal budget system (since day centres were not easy to finance from personal budgets).

9.a.ii ***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,[23] which might reasonably be taken to include standardised, shared electronic health records. 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, though, was of mechanisms for capturing evidence of patient experience for use in designing care coordination.

9.b Managerial discretion at provider level

For care coordination to occur, it was necessary not only for providers to join the relevant care networks, but also, as an SDO study on networks[258] suggested, to implement internally the networks' rules and working practices for care coordination. Some of our patient interviewees noticed (*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 front-line workers or the patient, or to be acted on.

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

1. Whether to target interventions on 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 nurse practitioners on high-admitting nursing and residential homes only.
2. Whether to mandate attendance at inter-agency team meetings; in Eastmere and Fivecastles attendance was otherwise erratic.
3. Whether 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 coordinating 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 co-locating them at general practices.

Care coordination, 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:

> **CPN:** *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?'* (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 inter-professional and inter-organisational 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.

9.c 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, multi-agency 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 five 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

> **Social Care Manager:** *short-term responses to the tier four emergency issues that* [trust name] *were having* (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

> **NHS Trust Manager:** *actually broke away from the currency of the health service being dominated by the acute sector.* (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:

> **NHS Trust Manager:** ***w****hat I saw was a very traditional and very unhelpful social worker versus GP clash* (TP01)

and a board that, some suggested, had little experience of or support for the public sector.

4. *Role and adequacy of community health services and primary care*: the trust was not an implementation of, say, the Kaiser Permanente model, but based on

> **NHS Trust Manager:** *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.* (TP01)

'Traditional' appeared to mean some GPs thinking:

> **NHS Trust Manager:** *If in doubt, I'm going to use the hospital* (TP01)

and (as others also thought):

> **NHS Trust Manager:** *the desire to preserve professional independence and economic independence*. (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):

> **NHS Trust Manager:** *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.* (TP01)

5. *Timing*: Before the banking crisis struck there was too little time to properly

> **Social Care Manager:** *develop the relationships* [… and] *develop the mechanisms* [...] *in terms of getting a more integrated approach it is going to take us a while.* (TP09)

Certain NHS-wide governance structures also both enabled and constrained care coordination. 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 six-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.

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 coordination, 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[69,70] and it has undergone neo-liberal 'reforms' with choice and competition.[259] Although the most common model is a health centre (*vårdcentral*), it contains diverse organisational forms of these, including diverse ownership. Its *vårdcentral* and *narsjukvard* centres, described below, were one source of the 'polyclinic' concept in English health policy (see *Chapter 1*). Given our research questions, Sweden makes an informative comparator to 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 coordination (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 coordination 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 coordination 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 to 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 primary health care centres (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 PHC service: part of a larger not-for-profit private foundation, with salaried doctors and one primary care doctor-centred PHC service based at a hospital.

All are funded by Stockholm county council (SLL), as described below, but SLL only directly manages Liseberg and Djursholms läkarmottagning.

10.a 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 the PHCC geographical catchment area were assigned to that centre. Certain PHCCs offer 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 can buy some private services (e.g. nursing, social services, home care) to supplement or replace public services. Social services are normally provided by municipalities (municipalities are smaller local authorities and separate to but encompassed within the larger counties). As in England, Swedish citizens co-pay for social care when they are over 65, and the assessment of individuals’ social care needs is separated from service provision.[260] Home care can 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 PHC providers,[261] which is said by some[262] to favour bigger and/or horizontally integrated providers. Under this system:

- Patients can choose their primary healthcare centre 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 healthcare commissioners.
- All providers are paid from public budgets, supplemented by patient co-payments that are the same for all providers and limited to SEK1,400 (€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 inter-organisational collaboration.

Independent cooperatives 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 *versus* 79% in 2005) and an increase in private for-profit ownership (25% in 2011 *versus* 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 1,000 ‘private’ doctors nationally also provide care on an FFS 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 last 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).

10.b Public polyclinics and care coordination

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 Stockholm county council for more in-depth study. Djursholms Läkarmottagning employed six doctors (one part-time) and four district nurses. Lisebergs Vårdcentral served 8,500 patients registered with doctors at the centre, and patients at a care home for older people and two homes for disabled people. About 1,000 of its registered patients lived outside this centre's geographical catchment area. Kista had 13,500 listed patients (60% non-Swedish background) and provided services to two nursing homes and eight homes for disabled people.

10.b.i ***Care coordinator***

Having chosen a PHC centre, 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 coordination predominates. Typically, the doctor will transfer the patient to the polyclinic-employed or -based nurse. Referrals to a physiotherapist, speech or occupational therapist, 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 PHC centres say that one of their nurses 'coordinates care', especially for complex cases, but the amount of coordination 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 survey[254] suggested that case management schemes were not widely used. Only a 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 under-developed, under-specified and subordinated to the consultation model of care coordination. 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 coordinator role in some mental health services. A psychiatrist or nurse 'case coordinator' will invite others to a needs assessment and care planning meeting. In one area in Stockholm (Sodertälje), a psychiatric care coordinator and a municipality case manager will work together, each coordinating other personnel from their respective health or municipality services. When these coordination 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.

10.b.ii ***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).

10.b.iii ***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 out-reach sessions. Djursholms Läkarmottagning had six doctors and four district nurses, but no specialist out-reach 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 out-reach geriatrician clinic, seven district nurses, six unqualified staff and extensive physiotherapy services. A privately owned diagnostic laboratory was co-located 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, not the county council, and no other *vårdcentral* uses 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, then make home visits for the next week. It was not clear to us whether nurses also made home visits to patients inside their area but registered with other polyclinics. *Vårdcentrals* also undertake population-oriented public health activities like maternity and well-baby clinics, vaccinations and care in the community.

Therapists (physiotherapists, occupational therapists, 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 out-patient departments. There is no separate out-of-hours service like in the NHS. ED visiting rates are high.

10.b.iv ***Coordination mechanisms within a single organisation***

Vårdcentral primary healthcare centres have a hierarchical organisational structure in which the doctors, nurses and (in some) therapists employed are managed in one unit and subdivided into multidisciplinary teams. 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 coordinating director, who in turn reports to the director of the Stockholm county division of primary healthcare and mental health (SLSO).

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 overridden 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, multidisciplinary teams 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 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' electronic health record (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 healthcare 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, hospital and other authorised healthcare providers. (There is no shared EHR.) In Stockholm and most other regions, one health IT system that does enable coordination and collaboration between patients and their care providers is Mina vårdkontakter[264], an encrypted service for patients to access and help coordinate 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.

10.b.v ***Vertical coordination***

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), PHC 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 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 less than the cost to the municipality of arranging nursing home or home care. *Nårsjukvard* 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 in-patient care besides the primary care described above.

10.c 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 above).

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 CEO 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. Stockholm county council and Norrtälje municipality jointly let the buildings that TioHundra AB uses to the provider. The PHCC director is accountable to the head of PHC 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 two 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- (‘micro’-) level changes to improve coordination.[34] 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 coordinated 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 coordinating care, and the inherited profession- and service-based communications and records systems.[34]

10.d 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 regarding the care coordination arrangements described above.

10.d.i ***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 Stockholm county council. In it are co-located other council-run services: a laboratory, a hospital, psychiatric services, a hospital out-patient gynaecological clinic (*mottagning*) and a geriatric clinic. An X-ray service, orthopaedic service and private pharmacy are also co-located there, but no social services, hospital specialist clinics or private practitioners.

The doctors buy managerial support services from a larger partnership, Praktikertjänst AB, of which:

> 'Our 2,000 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.'[265]

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 healthcare. 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).

10.d.ii ***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 co-located there. Stockholms Sjukhem has a contract with the county council to provide the primary care doctors, and employs the doctors and 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 dischargees). Palliative care is accessed by referral; other nursing home care is not.

10.d.iii ***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 (defined as above). Assistant nurses provide home care services (*hemtjanst*). Social care assessors (*biståndsbedömaren*) arrange separate home services and personal care services from the county or municipality.

To coordinate care for some patients, the PHCC district nurses needed to cooperate with the social care assessors. Both parties considered themselves care coordinators, but there are no formal systems to ensure coordination, 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 Capio 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, hence not tending to pass tasks on to others when they can.
5. There are stable systems (e.g. telephone numbers do not change) for faxing, telephoning and exchanging information. In acquiring another firm, Capio also acquired its electronic 'deviation' (adverse event reporting) system, which was initially not interoperable with Capio's own.

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

10.e Survey findings

10.e.i ***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 (8,500). 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, asthma). 30% reported a positive financial impact for investments in raising the quality of diabetes care compared to 34% for the national sample, 4% for heart failure improvements compared to 13% nationally. Equally, though, Stockholm centres were less likely to report negative financial impacts (2% Stockholm *versus* 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 tifferences 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% *versus* 27% for all of Sweden).
2. 23% fewer in Stockholm said that they had a patient discharge summary available (70% *versus* 93%).
3. 27% more in Stockholm said that they had laboratory results available electronically (94% *versus* 67%).
4. 10% more had warnings of potential drug interactions (80% *versus* 70%).
5. 8% more had reminders at the point of care (46% *versus* 38%).
6. 4% fewer had some e-mail contact with patients (47% *versus* 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. 14% fewer did this for diabetes than in Sweden as a whole (25% of PHCCs versus 39%), 12% fewer for coronary heart failure (27% *versus* 39%), 9% fewer for depression (22% *versus* 31%) and 20% fewer for asthma (25% *versus* 45%).
2. Fewer non-medical services were used, especially for coronary heart failure, which was 19% less than the national average (14% *versus* 33%). For diabetes it was 5% less; for depression 11% less; and for asthma 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% for asthma and none 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, though, even the top figures were low.
5. More PHCCs had lists of patients with the four diseases (coronary heart failure, depression, diabetes, 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% *versus* 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% *versus* 24% for all of Sweden) and 11% more for diabetic patient quality indicators (60% *versus* 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.

10.f Care coordination and integration in Swedish primary healthcare

In Sweden, much was achieved for continuity of primary healthcare 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 coordination in the NHS, implications for the NHS (RQ5) 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 an 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 WTE doctors (*Puls*e, 27 June 2014).
3. Scope for managerial discretion (RQ3) 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 inter-organisational care coordination (RQ1):

   (a) Inter-organisational 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 under-development.

(b) 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 inter-organisational care networks and their coordinating bodies alongside the primary care doctor's coordinating role was unnecessary (and not observed).

(c) Administrative 'round trips' from another provider to the general practice and back again to obtain budgetary authorisations.

(d) Even though pooled budgets (where they existed) removed financial obstacles to referrals, some administrative barriers (e.g. social care assessment) remained.

(e) Mismatched financial incentives and managerial targets between different provider organisations.

(f) Separate location of primary medical and district nursing services and their staff.

Removing these barriers did not make care coordination completely unproblematic, but the remaining problems of both horizontal and vertical coordination were similar to these that might be found within an NHS trust (above all, dealing with strong, somewhat separatist professional cultures; geographical separation of services).

5. The difference that ownership made (RQ2) 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).

CONCLUSIONS

11 Conclusions

11.a Summary Empirical Findings

We summarise our empirical findings by research question.

11.a.i ***RQ1: Integration versus network***

RQ1a. Horizontal integration, hierarchy and networks

We compared two partly horizontally integrated trusts (CHS with mental health in Whinshire; 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 (*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 coordination and continuity of care.

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

1. Consultation model of care coordination with:
    a. primary care doctor as the captant professional;
    b. case management.
2. Interdisciplinary care teams (often several in parallel).
3. 'Virtual ward' or 'hospital at home' models of care, though 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. Co-located services.

The following obstacles to care coordination 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 primary health care centre and municipality, 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 coordinating their own care varied. Discrepant working practices, even within one manager's span of control, insofar as the differences reflected different technical tasks (e.g. maintaining tissue viability *versus* managing heart failure).

Yet within the care networks that we studied, the following barriers to care coordination 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 coordination 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 inter-organisational links.
6. Mismatched financial incentives and managerial targets.
7. Organisational separation, which often meant separate locations.

The more inter-organisational 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 inter-organisational interfaces that had to be negotiated. The same applied when multiple care networks had sedimented[267] over time. In these respects our findings converge with some of those in the evaluation of London polysystems.[49]

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

1. Creating line-managerial accountability for achieving the coordination of care, e.g. 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 in-patient and domiciliary care and between health and social care were reported usually to be easy, flexible and swift compared with equivalent referrals across inter-organisational boundaries. The same was true of Swedish polyclinics. Other studies[143,268] 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 co-located by default, although the ‘location’ might be a locality with staff working across it. In care networks separate location was the default. Then, co-location 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 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 under-development.
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 coordination processes within the integrated organisations appeared to be more favourable to producing the continuities of care than were care network structures.

RQ1b. Vertical integration, hierarchy and networks

With adjustments, analogous findings and conclusions apply to vertical coordination. We found certain additional care coordination mechanisms, this time for vertical coordination, 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 PHC professions have read–write access (provided that patients consent to this).

Certain obstacles to vertical care coordination were found in both integrated organisations and care networks:

1. The consultation model required in some cases referral via a GP, 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 often 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 coordination were similar to those for horizontal coordination of care. On balance, therefore, the integrated organisations also appeared more able to accommodate vertical care coordination processes, and therefore to producing continuities of care, than did care network structures.

RQ1c. Cost information

CCGs reimbursed general practices or gave them budgets for additional care coordination 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, either according to a DRG-like tariff (the HRG) for most acute hospital and some mental healthcare 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-coordinated or more continuous care. These payment systems are standardised across England, 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 coordination 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.[56] Hence the care networks were not well placed either to know whether their care coordination mechanisms (e.g. case management, MDT etc.) saved cost compared with previous (or no) care coordination methods, or which coordination 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.

RQ1d. Diversity of services

Both for integrated organisations and care networks, the simplest way, in the short term, to gain access to additional services for their patients was either to co-locate or subcontract these services; as our general practices did for social support and leisure (exercise) services, respectively. As we have seen, though, these network mechanisms came at the price of certain obstacles to care coordination, compared with organisational integration. Whether 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 coordination. Further research is required to specify the scale at which the balance of advantage shifts.

11.a.ii ***RQ2. 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[76,269]), 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 community health services 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 community health services 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 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 coordination because of its impact on GP workload); and the scope for medical innovation.

11.a.iii **RQ3. 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, Tarrow).Clinician advocates were equally important for introducing and promoting projects and maintaining close working relationships at senior medical management levels across organisations.[264]

As more concrete managerial practices that promoted care coordination 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. White-lists 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. Inter-operable ICT (e.g. conforming to open standards for data sharing).

11. Hosting or outposting services, or seconding staff, to achieve co-location.
12. Allowing time and stability for working relationships to develop across organisations.
13. Mandating staff participation in inter-agency and inter-disciplinary care teams when necessary.
14. Education, training and culture management to breach inter-professional 'silos' and promote inter-organisational working (see below).

We accept that in times of austerity and high GP workloads some of the above may seem counsels of perfection. To that list we therefore 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.

11.a.iv **RQ4. Predicted differences between integration and networks**

Wider implications of this research for organisational theory and other disciplines will be addressed in future peer-review publications arising from this project. Here we focus on the main hypothesis arising from our overview (*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 coordination, and therefore continuities of care, than coordination by care network.*

Some detailed findings that tend, on balance, to support this hypothesis are outlined above. Care coordination 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 coordinating bodies exist partly as a workaround for this problem. It might therefore appear that a single-provider model of primary care would improve care coordination 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 inter-disciplinary teams based on care groups or care plans, hence relying heavily on 'matrix', 'organic' or 'project' methods of management, with highly standardised and (so far as consistent with patient confidentiality) open information and communication systems. It would depend much less on multi-agency 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 cooperative, 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.[265]

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

11.a.v RQ5. 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: that of ascertaining what aspects of patients’ experience it is 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 coordinate 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 less their capacity for coordinating and managing their own care. The implication is that healthcare providers need a better understanding of how patients coordinate 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 1980[266]) 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 coordinating a patient's care and strengthening continuity of care. Recording and sharing a care plan requires, however, information systems which capture this (and the supporting clinical) information, and allow the relevant professionals shared access to it.

Provider management

For healthcare 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 co-location 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 illustrate a dearth of the requisite skills among commissioners and, so far, 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 coordination. 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.

11.b Revisions to the initial analytic framework

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

In the consultation model of care coordination, 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 coordinating her care overall. When case management schemes are added to care coordination by a primary care doctor, two parallel 'consultation model' structures operate simultaneously, creating additional coordination tasks. The production of continuities of care requires not just that care coordinators and care plans exist, but that each patient has just one care-coordinator with overarching responsibility for her care, and correspondingly one over-arching care plan.

The co-location of organisation appears, in practice, to have little practical effect on the linking of formal IT systems, even though it facilitates informal information exchange (informational 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 inter-professional and inter-agency 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 produce flexible and informational continuity. In our view these relationships merit further research.

11.c Limitations and qualifications to the findings

Our purposive sample of patients was drawn to select patients with specific health problems, 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, 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 coordination mechanisms than the services that our patient sample had mostly experienced, such coordination mechanisms may have been omitted from this study. Some coordination mechanisms that we could study, though, did also extend to the under-represented services (e.g. the consultation model, multi-agency teams) and these mechanisms tended to be generic and important ones in local health economies overall.

Because of the focus of our research questions, 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 coordinated 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 narratives[267] or of nuanced attitudes (e.g. the NHS in general as good *versus* their particular experience as poor). e could validate their accounts of their contacts with services, and to some extent of their experiences of care coordination, 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 coordination 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 11* compares certain characteristics of our study general practices, as evidence of how typical the care coordination activities and management within them are likely to be of others in England.

Table 11: Study general practice characteristics

	GP head-count	Practice list	Contract	Teaching practice?	Has GPSI?	QoF score above (+) or below (-) England mean	Ownership
Fivecastles	3	3,500	GMS	Y	N	+	Corporate
Eastmere 1	6	9,000	GMS	Y	Y	+	Partnership
Eastmere 2	5	4,500	GMS	N	N	+	Partnership
Sedgeton 1	5	7,500	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	9,000	GMS	Y	N	+	Partnership
England mean/mode	4.42*	7,041	GMS	N	N	N/A	Partnership

*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, hence perhaps more likely than other general practices in practical terms to support initiatives to set up care networks and enhance care coordination 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 coordination. If so, this study may err towards over-estimating the extent and variety of care coordination 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 11*, 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.

11.d 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, then outwards to the care network factors that produced or constrained care coordination at an organisational level, 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 coordination mechanisms which are partly behind-the-scenes so 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, produced some explanations about how and why care coordination occurred, or failed to. The method therefore appears worth 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 coordinating 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 coordinate 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' coordination of their own care and are complementary to it.
5. Whether the assumptions that there are economies of scale in centralising community health services at locality level, and that the benefits of doing so outweigh the informational, flexible and relational continuity advantages of co-locating 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 (co-location, 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 coordination interacts with a care pathway model of care coordination, 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 coordination, but it remains unclear what other incentives might stimulate more or better coordination 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 to synthesising the results and to 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.

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

Richard Byng (Professor, Primary Care Mental Health) contributed to the research design, case study 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.

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Appendix 1: Care coordination by the patient

Although often viewed as passive, most patients expect to and can have a role in coordinating their own care[1]; and when health professions fail to coordinate care, they sometimes have to do so.[2] Care coordination by the patient herself depends on the patient using 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 coordinate 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.[3,4]

The severity of the condition and the level of distress have been found to be strong predictors of help-seeking for mental health problems.[5] 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).[6] 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 gender to the patient.[7] Patients who believe that they can 'manage by themselves' are less likely to disclose their problems to the GP.[8,9] Neverthless, 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.[8]

The burden that the task places on patients and their carers is one limit to patients' self-coordination of care. There are appear to be limits to how far patients are usually willing to travel to receive secondary care,[9] 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.[10] 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.[11] 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.[12,13]

For mental healthcare, seeking help from formal services depends also on how the patient perceives her likely reception. Patients' perceptions of a GP's competence, openness, social distance (lower socio-economic status patients perceive GPs to be higher in socio-economic 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 her problem.[5] Fear of rejection, shame and embarrassment are emotional barriers to psychological treatment.[13,14] Patients' expectancies of treatment have also been found to affect help-seeking:[15] for example, patients may believe that the GP will only prescribe anti-depressants. Among people with depression, women perceive more barriers than men do to accessing help.[16]

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 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 transport[17] – when deciding where to refer a patient. Two studies[3,18] of patients' and clinicians' views on the aims and benefits of care coordination note that these sometimes differ, although a third (small) study of acute care[19] suggests the opposite.

So 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.[20] Patient intelligence and ability to articulate problems are related to psychological mindedness, which has been found to predict benefit from therapy.[21] 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.[20] 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.[22] 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.[23–25] 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.[26]

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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' coordination 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 coordination. 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).[1]
3. Owner-managed small firms (personal income, asset value).
4. Social enterprises (normative and local aims).[2]
5. Producer cooperatives (personal income, economic security, control over work).
6. Voluntary organisations (normative aims).[3]
7. Public firms (policy implementation).
8. Hybrids of the above.[4]

Having different owners, objectives and internal managerial regimes,[5–7] 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 coordination and continuity outlined in Chapter Error: Reference source not found (coherence of rules and policies at different organisational levels[8])?

For example, social care networks in England, France and Germany appear spontaneously to separate profit from non-profit services.[9] (The situation is similar among commissioners; and US commercial insurers are more likely than Medicaid to promote managed care.[10]) In social care, low wages leading to high staff turnover are an obstacle to maintaining relational continuity of care.[11] A small qualitative study[12] 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 coordination centres are co-financed with banks and insurance companies 'looking for cross-selling opportunities'.[9] Evidence on these questions is sparse, mostly indirect and equivocal.[13,14] Providers owned by organisations that also pay for healthcare (e.g. Veterans Administration, Kaiser Permanente, Group Health; and the NHS) appear to give care coordination 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.

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Appendix 3: Case study site vignettes

Site 1: Eastmere

Eastmere is a large, very rural county with some areas with consistently high levels of deprivation. Its population of circa half a million 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 county-wide unitary authority was created. Health was similarly disaggregated (following the district council boundaries before a process of gradual consolidation). There is now a county-wide Care Commissioning Group (CCG) divided into 10 GP localities.

A county-wide community interest company provides adult community health services (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 county-wide 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 (c. 8,500) and was a training practice, the other of below-average size (c. 4,500), with a high proportion of patients with long-standing conditions. Both scored highly in term 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 coordination 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 multidisciplinary team 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 with 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 ICP. 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 community ANP. They produced both a goal-centred care plan (focusing on long-term condition management) and an anticipatory care plan and they meet 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 healthcare 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 or over, compared to over 21% in study areas 1 and 4 (the national average is 16.3%). Using the IMD2010 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 co-located 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 out-patient 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 in-patient 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 co-located 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 'integrated primary care teams' (IPCT). These serve clusters of GP practices (although none is co-located), with the studied 'polyclinic' forming the centre of one such cluster. The IPCTs are multidisciplinary, including advanced care practitioners (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 multidisciplinary team 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 district nurse, physiotherapist and occupational therapist.

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 less 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 district general hospital with accident and emergency, maternity, intensive care, medical and surgical specialities. Yet 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 LA/PCT commissioning for healthcare. At the start of our study period, Tarrow provided *integrated acute, adult community health services 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 county-wide Clinical Commissioning Group (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 coordination model. This was to include rapid response/instant care, intensive home support (up to six-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 healthcare assistants, and also inter-organisational by virtue of both a central role for GPs and the inclusion of social care staff as partners. Elements included multidisciplinary team 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/inter-organisational 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. Whilst a significant proportion of its population live in rural areas, it has an essentially suburban character and is best described as an affluent home counties commuter area. It ranks highly not just in terms of GDP 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 healthcare for the NHS. The parent company operates a number of GP surgeries and GP-led health centres in the UK on behalf of healthcare 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 like 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 ENT. 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 out-patient 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 multi-agency groups have been rolled out across the county, and involve a core group of professionals comprising GP, practice nurse, adult and community health team, mental health, social worker, community practice worker and a care coordinator (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 PIS.*
- *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?

<u>Case management</u>

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?)

<u>External Referral</u>

- What are the main transfers or referrals to <u>external</u> organisations or other sources of care?
  - Are any of these co-located 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 co-location?
- 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. EBM-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 PIS.*
- *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

2. 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:

3. 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			

4. Do you have any support from social services/care agency etc. because of your health/to help you cope at home?

5. Over the past 12 months how would you say your health has been...?

Excellent Very Good Okay Not so good Poor

Your healthcare

6. Can you talk me through how your health has been over the last 12 months?

Use Table 1 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

7. 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*

8. 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 in-patient/out-patient

8.1 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

9. 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

10. Overall, do you find it easy to see someone about your healthcare? YES/NO

Discuss why:

....[Free text]

Organisation of healthcare: Care manager

11. Do you think it is important that you have someone who is responsible for coordinating your care?

11.1 Who do you think has the best overview of your care at the moment?

PROMPT – Do you have a designated care manager/is more than one person responsible/what about the quality of this relationship?

11.2 Has this person changed in the last six months? YES/NO

IF YES

11.3 Why was that?

....[Free text]

12. 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

Can I ask you how far you agree with the following statements?

12.1 My doctor/care manager always has time for me and treats me as an individual

Strongly Agree Agree Disagree Strongly Disagree

12.2 It is very important to me that I see my regular doctor/care manager

Strongly Agree Agree Disagree Strongly Disagree

Care plan/team working

13. Are you aware of a plan for your care?

If Yes: Have you seen it or contributed to it?

13.1 What happens in practice – is anything written down? Where is it kept?

14. Can I ask you **how far do you agree** with the following statements?

14.1 It is important that the people looking after me have a shared plan for my care and treatment

Strongly Agree Agree Disagree Strongly Disagree

14.2 The people looking after me work well as a team

Strongly Agree Agree Disagree Strongly Disagree

15. 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?

15.1 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

16. How important is it that your healthcare is the subject of regular review and monitoring

Very important Important Not very important Not important at all

16.1 How often is your condition reviewed [as opposed to responding to changes]? Who conducts the review?

....[Free text]

16.2 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?

17. 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:

17.1 What about communication with social services?

Do they know what healthcare you are receiving/what do they need to know?

17.2 And what about with you? How would you describe the amount of information you receive to help you manage your health?

Can I ask you how far you agree with the following statement?

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

18. Do you know how your records are kept?

Can you add information? Who can add information?

....[Free text]

Patient involvement

19. How much have you participated in deciding how you are looked after?

19.1 Are you involved as much as you want to be in decisions about your care and treatment?

19.2 What information about you do you hold/think you should hold about your care/treatment?

19.3 Do you feel sufficiently supported to manage your own care?

Absence of interruptions or gaps

20. Have there been any interruptions or gaps in your care? For instance,

any waits, delays, bottlenecks or other interruptions?

....[Free text]

IF YES

20.1 What do you think caused them?

Prompt – aware of reasons?

....[Free text]

21. Overall, what do you think works best about how all the services communicate about your care or coordinate their work to help you?

22. Do you think your care could be better organised?

IF YES

22.1 In what way?

....[Free text]

Finally

23 Is there any other important aspect of your healthcare over the last 12 months which we have not yet asked about?

....[Free text]

What did you do before you retired?

Does your family live nearby/help out?

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 / Panic attacks/ Psychosis / Schizophrenia / Bi-polar 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 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 HEALTHCARE?

1. At home

2. At GP (or equivalent) clinic

3. At another primary care clinic
4. A&E
5. Out-patient at hospital
6. In-patient at hospital
7. Community hospital, nursing home or similar (intermediate care)
8. Residential care
9. Other place(s) (where?)

Table 1: Health

	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		

Overview – Last 12 months