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Ideas that change
health care

Co-ordinated care for people with complex chronic conditions

Key lessons and markers for success

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Key messages

Based on a comparative analysis of five UK-based case studies of care co-ordination programmes for people with long-term and complex chronic conditions, this report examines key lessons and markers for success in the 'how' of care co-ordination that might be transferable to different contexts and settings.

In terms of the process of care co-ordination, the following factors appear to be important design features.

- At a *personal* level, a holistic focus that supports service users and carers to become more functional, independent and resilient, and to live well by managing their conditions in the home environment, is preferable to a purely clinical focus on managing or treating medical symptoms.

- At a *clinical and service* level, it is important to encourage multiple referrals into a single entry point where care co-ordination can be supported. Named care co-ordinators are needed to support the process of care co-ordination by providing a source of personal continuity to patients and carers as well as enabling access to care through multidisciplinary teams.

- At a *community* level, the role of members of the local community should be seen as integral to the care-giving process. Building community awareness and trust promotes legitimacy and engagement, which can provide an essential resource within care co-ordination programmes.

- At a *functional* level, effective communication between members of the multidisciplinary team is essential. There is a need for shared electronic health records to support the process, but a 'high-touch, low-tech' approach has value in promoting face-to-face communication, fostering collaboration and enabling meaningful conversations about the needs of patients with complex needs.

- At an *organisational* level, effective targeting of service users is required to prioritise care provision. Programmes of care co-ordination need to be localised so that they concentrate on specific communities and neighbourhoods. Local leadership and long-term commitment from commissioners and providers is important to establish a shared vision and to challenge silo-based thinking.

- At a *system* level, integrated health and social care commissioning can support longer-term strategies and provide a greater degree of stability. A political narrative that supports person-centred care co-ordination provides credibility when developing new ways of working.

When implementing care co-ordination in different contexts and settings, the following key lessons can be drawn.

- There is a chronic lack of evaluation and measurement on which to judge the performance of care co-ordination programmes. This is a fundamental weakness; far greater attention is required to measure, evaluate, compare and reflect on performance.

- It can take some years for programmes of care co-ordination to mature – and to build the necessary legitimacy and capability for them to become accepted by both professionals and patients.

- Successful approaches to care co-ordination have highly context-specific case histories, and models of care cannot simply be transported 'en bloc' from one setting to another. Understanding one's own local context is the key to learning lessons and successfully transferring approaches from other programmes of care.

- Care co-ordination programmes appear to flourish at the neighbourhood level where the benefits of engagement with local communities sit alongside the need to have close working relationships within multidisciplinary care teams dealing with manageable caseloads.

- There is potential to scale up operations through building a number of locality-based approaches to care under the direction of an umbrella organisation. Such an approach might have a bigger impact in improving cost-effectiveness, which otherwise appears to be limited.

- Care co-ordination needs to be taken forward primarily as a quality improvement strategy rather than one specifically aimed at reducing costs.

- Across all of the five case study programmes, the apparent disengagement of general practitioners (GPs) was a cause for concern; it made information exchange more problematic and limited the ability to bring their general knowledge of the patient/ family into discussions about care.

- Weak links with secondary care need to be addressed to ensure better quality transitions from hospital to home, to reduce readmission rates and secure faster access to specialist knowledge in the care process.

- Models of care co-ordination are likely to be more effective when they operate as 'fully integrated' provider teams with a degree of operational autonomy.

- Without full alignment across the political, regulatory, organisational and professional spectrum towards the goals of co-ordinated care, too much reliance is placed on local leaders to make change happen.

About the authors

Nick Goodwin is a social scientist, academic and policy analyst with a special interest in investigating the organisation and management of primary, community and integrated care. Nick is co-founder and CEO of the International Foundation for Integrated Care, a not-for-profit membership-based foundation dedicated to improving the science knowledge and application of integrated care and is Editor-in-Chief of the *International Journal of Integrated Care*. Nick also works as a Senior Associate at The King's Fund, London, supporting its programme of research and analysis for improving and integrating care to older people and those with long-term conditions.

Nick is very active in research, development and support for integrated care at both a political and practical level. He continues to work with the UK government to support its policies on integrated care, including the evaluation of its health and social care integration pioneer programme. Nick supports international commitments to the application of integrated care within the European Union as part of the research team Project Integrate and the European Innovation Partnership on Active and Healthy Ageing. Nick is leading work for the World Health Organization to support the development of a global strategy to develop person-centred and integrated care.

Lara Sonola is a senior researcher in the Policy Directorate of The King's Fund. Her current interests include continuity and co-ordination of care, intermediate care and service reconfiguration. Lara joined The King's Fund in 2009 to work on The Point of Care programme, while completing her Masters.

Prior to this role, she worked in the Faculty of Medicine at Imperial College London during the establishment of the UK's first Academic Health Science Centre. She also managed scientific projects at the Food Standards Agency.

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Before focusing on health policy, Veronika worked extensively on access to finance policies for the poor, researching banking and financial regulation as well as microfinance. During her time at the New Economics Foundation, she contributed to the discussion on funding and social enterprises in the delivery of public services and pro-poor interventions.

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Prior to his academic career, Dennis held several senior leadership positions at a teaching nursing home, continuum of care health system, health maintenance organisation and hospital. He is well-known for his pioneering work as CEO of Elderplan Social HMO pilot.

Dennis is the author of a number of publications on integrated care, serves on the editorial board of the *International Journal of Integrated Care*, and is co-founder of the International Foundation for Integrated Care. He is a fellow of the Gerontological Society of America and received the 1999 Key award in Gerontological Health Policy, Practice, Research and Education from the American Public Health Association.

Acknowledgements

Preface

Co-ordination of care for people with complex chronic illness is a global challenge. Driven by broad shifts in demographics and disease status, age-related chronic and complex medical conditions account for the largest share of health care budgets internationally (Epping-Jordan *et al* 2004). However, people living with multiple health and social care needs often experience a highly fragmented service, leading to sub-optimal care experiences, outcomes and costs. To address this, strategies for care co-ordination have been developed in many countries, yet evidence suggests that many such innovations have not achieved their objectives and the failure rate has been high (Goodwin 2011). In particular, there remains a lack of knowledge about how best to apply care co-ordination in practice.

About this report

This report brings together the key findings from a two-year research project funded by Aetna and the Aetna Foundation (The King's Fund 2013). The overall aim of the research was to understand the components of effective strategies that have been used in the United Kingdom to deliver co-ordinated care for people with long-term and complex needs. In addition, the research sought to tease out the key lessons and markers for success to help identify how care co-ordination could be transferred from the UK to the US context.

The research involved an in-depth investigation of five UK-based programmes of care co-ordination for people with complex needs, which were selected on the basis that they had been successful in moving towards meeting the 'Triple Aim' challenge (Institute for Healthcare Improvement 2013) of improved care experiences, better care outcomes and more cost-effective service delivery. This report provides a synthesis of our findings. Separate reports on the experiences and impact of each of the five case study programmes have been published by The King's Fund (Sonola *et al* 2013a, 2013b; Thiel *et al* 2013a, 2013b, 2013c). A summary of the research methods used to select and investigate the five case study sites is provided in Appendix A.

Introduction

What is care co-ordination?

The term 'care co-ordination', like 'integrated care', does not have a universally recognised definition. For example, it is often used synonymously with 'case management', 'disease management' or 'multidisciplinary teams' (McDonald *et al* 2007). Indeed, the terms 'co-ordination' and 'integration' are frequently used interchangeably, though the former tends to refer to patient-focused or clinical interventions while the latter focuses on organisational or managerial issues (Kodner 2009). The following definition from the National Coalition on Care Coordination describes the typical components of the approach:

> *'Care coordination' is a person-centered, assessment-based, interdisciplinary approach to integrating health care and social support services in a cost-effective manner in which an individual's needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator.*
> (National Coalition on Care Coordination 2011)

However, reviews of the concept recognise that care co-ordination may be achieved in many different ways to deliver the common objective of facilitating a more proactive approach to bringing care services together around the needs of service users (McDonald *et al* 2007; Van Houdt *et al* 2013). Hence, care co-ordination consists of a range of strategies that seek to create more integrated and person-centred care across various settings (Hofmarcher *et al* 2007). Broadly speaking, the approach entails making care systems more attentive to the needs of individual patients and ensuring that they get an appropriate package of care that seeks to stabilise their health over long periods and in less costly environments. Care co-ordination, therefore, is particularly relevant to patients with chronic and complex medical conditions who may find it difficult to navigate fragmented health care systems.

The growing importance of care co-ordination in the United Kingdom and the United States

In both the United Kingdom and the United States, despite significantly different systems of care (*see* Table 1), person-centred care co-ordination is now widely recognised as a critical component of privately and publicly funded health care. It has been especially applied in the clinical management of patients with complex and costly conditions whose needs cut across multiple services, providers and settings.

Table 1 outlines the main differences between the structure of the health and social care systems in the United Kingdom (England and Wales only) and the United States. These systems differ between the four countries of the United Kingdom (England, Scotland, Wales and Northern Ireland). There were no case studies in Scotland or Northern Ireland, so these countries have not been included in the table. The table highlights differences between England and Wales where applicable.

Table 1: Comparison of health and social care systems in the United Kingdom and the United States

	United Kingdom (England and Wales)	United States
Funding: health	Taxpayer-funded; private health care insurance is available, but the market is small	Multiple private and public sources, including private insurance, Medicare and Medicaid. Medicare: a social insurance programme for older people and people with disabilities funded through a combination of taxes, premiums and federal government subsidies. Medicaid: means-tested programme jointly run by the federal and state governments targeted at people with low incomes and insufficient means to pay medical bills. Medicaid eligibility and coverage vary from state to state
Funding: social care	Means-tested taxpayer funding with high levels of co-payments and self-funding	In the United States, social care is called long-term care (LTC) services and support. Medicaid is the dominant source of payment for LTC, followed by self-funding and co-payments
Cost to patient: health	Health care: free at the point of service	Health: depends on type of cover. Private: depending on health plan, substantial co-payment and deductibles. Medicare: private insurance to cover co-payment and deductibles. Medicaid: free at the point of service
Cost to patient: social care	*England:* patient pays full costs if they have assets of £23,500 or more; costs highly variable depending on need and location, and can be substantial. Introduction of higher self-funding threshold in 2016 will make more people eligible for free social care *Wales:* maximum co-payment of £50 per week	LTC: if Medicaid-eligible after meeting income and asset requirements (which vary by state), free at point of service
Commissioning and care provision: health	*England:* 211 clinical commissioning groups (CCGs) commission services from National Health Service (NHS), third sector and independent sector providers. Majority of services provided by NHS *Wales:* no internal market, regional health boards set strategies; no commissioning/provider split	There is no commissioning process in the United States *per se* Insurance companies, the state and the federal government enter into direct contracts with private, third sector and public providers The federal government and the states also enter into direct contracts under Medicare and Medicaid respectively with managed care plans and case management and other co-ordinated care programmes. Reimbursement arrangements in the private market vary by insurer and insurance product
Commissioning and care provision: social care	Assessments carried out by social workers (free); occupational therapists and physiotherapists employed by local authorities; personal care provided largely by private agencies commissioned by local authorities	LTC: *see* above. Depending on the type of LTC programme or service and state, assessments carried out by state or county social workers and/or nurses or by employees of provider organisations
Role of general practitioner (GP)	GP practices are independent businesses commissioned by the NHS as gatekeepers to secondary/specialist care; more than 90% of the population are registered with a GP. GPs operate increasingly in partnerships such as networks or federations. Other organisational forms are slowly emerging following the health and social care reforms in 2012. Patients can choose a GP in a geographically defined area near to their home	Primary care in the United States is provided by general internists, family physicians and nurse practitioners – ie, primary care providers (PCPs). Primary care provision can take a variety of forms – eg, independent practice association, health maintenance organisation or medical home Regardless of insurance cover or delivery arrangement, patient is generally free to choose their own PCP
Community care	Highly developed, with frequent co-location of community care staff in GP practices; low staffing levels may be a risk as levels of health care provision in the community increase	Highly developed LTC resources with major emphasis on providing home and community-based services (the equivalent of social care in the United States), especially in state Medicaid programmes. Links with primary care can be problematic in the fee-for-service sector, but strong connections in existing and emerging managed care/co-ordinated care/integrated care models

Table 1: (continued)

	United Kingdom (England and Wales)	United States
Sustainability issues: health	Increasing demand on all health services due to ageing population; current increase in demand on emergency services; £20 billion savings to be made by 2015, expectation of austerity/flat funding beyond this point	Increasing demand on all health services largely due to ageing population and chronic illness. Federal and state concerns about maintaining control over rising costs. The financial impact of the Patient Protection and Affordable Care Act 2010 is a major source of uncertainty with regard to sustainability
Sustainability issues: social care	Local authorities required to make large savings, roll-back of services observed in all five case study sites	LTC: *see above*
Policy drivers	Strong drive to improve vertical and horizontal integration; health reforms could see new providers entering the market in future	The Patient Protection and Affordable Care Act, signed into law in 2010, put in place important reforms of the US system; major emphasis placed on accountable care organisations and other integrated care models, which are taking centre stage in public and private markets

In the United Kingdom, case management and care co-ordination have become well established and have typically been provided through multidisciplinary and community-based health and social care teams, working to improve care post-discharge from hospital and/or to avoid hospitalisations by focusing on 'at-risk' individuals in the community (Ross *et al* 2011). While the approach has improved the experiences of users and carers alike, as well as enabling more cost-effective care in some localities, evidence for the effectiveness of such strategies remains mixed and limited; success appears to be highly dependent on the way in which care co-ordination is implemented locally (Curry and Ham 2010; Roland *et al* 2012).

In the United States, co-ordinated care arrangements are largely found in integrated delivery systems (eg, Kaiser Permanente), health maintenance organisations (HMOs) and other special 'carve out' managed care programmes (eg, the Program of All-Inclusive Care for the Elderly (PACE)) operating within a capitated or budgeted environment. Care co-ordination is a prominent feature of programmes supported by Medicare and Medicaid. For example, Medicare Advantage health plans, in which 20 per cent of Medicare beneficiaries are voluntarily enrolled, routinely provide care co-ordination services.[1] Special Needs Plans (SNPs) – a type of Medicare Advantage plan that provides intensively targeted care to 'special needs individuals' – are designed to improve care primarily through improved co-ordination and continuity of care.[2]

In both the United Kingdom and the United States, the need to encourage care co-ordination to tackle the rising demands placed on health systems by ageing populations with complex needs has become central to national strategies. In England, the case for person-centred care co-ordination has moved rapidly up the policy agenda to become a central theme in health and social care reform (Goodwin *et al* 2012). As a result, a shared cross-government commitment – the National Collaborative for Integrated Care and Support – was created in May 2013 with the aim of creating a new culture of co-operation and co-ordination between care sectors. This includes a more ambitious vision for rolling out integrated care 'at scale and pace' through 'whole-system' approaches promoted by the Department of Health's integrated care pioneer programme (Ham and Walsh 2013). The governments of Scotland, Wales and Northern Ireland have similarly pursued a range of reforms to support health and social care integration, though analysis

[1] Medicare beneficiaries have the option of receiving their benefits under Medicare Part A (hospital) and Part B (medical) through these private plans as an alternative to the federally administered traditional Medicare programme. Medicare Advantage plans, which are sponsored by for-profit and non-profit insurance and provider organisations, receive a capitated (per enrollee) payment to provide these covered services. The benefit package frequently includes benefits beyond the traditional programme (eg, foot care, optical services, etc) and may require an additional out-of-pocket premium.

[2] 'Special needs individuals' include: institutionalised beneficiaries (ie, nursing home residents); individuals with severe or disabling chronic conditions; and, 'dual eligibles' (ie, individuals, usually with complex conditions and needs, who are covered by both Medicare and Medicaid).

suggests that their focus on organisational restructuring has not necessarily led to the successful deployment of effective care co-ordination strategies at the clinical and service level (Ham *et al* 2013).

In the United States, two key national initiatives have been developed in recent years to promote care co-ordination: the 'medical home' and the 'accountable care organisation' (ACO). The medical home model is a physician-led, team-based comprehensive primary care model in which care co-ordination and innovative payment methods are designed to enhance quality outcomes and cost-effectiveness; medical homes are being developed in both the private and the public sectors. ACOs, on the other hand, are networks of physicians, hospitals and other health care providers that voluntarily come together and are held accountable for the quality and cost of the entire continuum of care delivered to a group of patients. While ACOs are being developed in the private sector, they are also now a key feature of the Medicare programme, with more than 220 Medicare ACOs having been established as of January 2013, potentially covering 4 million enrollees. Likewise, many states have shown an interest in the potential of the ACO model to co-ordinate care for Medicaid recipients.

At a national level, the Patient Protection and Affordable Care Act 2010 (ACA) in the United States has encouraged greater emphasis on care co-ordination, which has become one of six priorities in the recently adopted US National Strategy for Quality Improvement in Health Care (Agency for Healthcare Research and Quality 2012). Care co-ordination and the companion strategies were selected because of their potential to improve health outcomes and increase the effectiveness of care for all Americans. Created under the ACA, the strategy will guide local, state and national efforts to promote better health and quality of care for Americans.

Understanding the nature and benefits of care co-ordination: the need for closer investigation

This research involved a non-systematic review of the literature on care co-ordination for people with complex needs in order to develop some *a priori* criteria to act as a frame of reference for our investigations and findings. The evidence from this review suggested that comprehensive, systems-based solutions to care co-ordination have the potential to improve collaboration within and between various parts of the health care enterprise; they can encourage patients to become more proactive in the management of their own care, and so enable the delivery of better quality services (Devers and Berenson 2009; Ham 2010). Successful approaches to care co-ordination were found to contain a range of key characteristics (*see* box opposite), yet the lack of evaluation in this area means there is scant evidence to support a positive association between better care co-ordination and improved patient experiences, care outcomes and financial efficiencies (Øvretveit 2011). This is particularly true for people with complex long-term medical conditions and multiple needs (Bodenheimer 2008).

Characteristics of successful approaches to care co-ordination

System level

- Universal coverage or an enrolled population with care free at point of use
- Primary/community care-led
- Emphasis on chronic and long-term care
- Emphasis on population health management
- Alignment of regulatory frameworks with goals of integrated care
- Funding/payment flexibilities to promote integrated care
- Workforce educated and skilled in chronic care, teamwork (joint working) and care co-ordination

Organisational level

- Strong leadership (clinical and managerial)
- Common values and a shared mission
- Aligned financial and governance structures
- Integrated electronic health records
- Responsibility for a defined population or service
- A focus on continuous quality measurement and improvement

Clinical and professional integration

- Population management
- Case finding and use of risk stratification
- Standardised diagnostic and eligibility criteria
- Comprehensive joint assessments
- Joint care planning
- Holistic focus, not disease-based
- Single or shared clinical records
- Decision support tools such as care guidelines and protocols
- Technologies that support continuous and remote patient monitoring

Service integration

- Assisted living/care support in home
- Single point of entry
- Care co-ordination and care co-ordinators
- Case management
- Medications management
- Centralised information, referral and intake
- Multidisciplinary teamwork
- Inter-professional networks
- Shared accountability for care
- Co-location of services
- Discharge/transfer agreements to manage care transitions
- Supported self-care

Sources: Bodenheimer 2008; Coleman *et al* 2009; Curry and Ham 2010; Goodwin *et al* 2010; Ham 2010; Hofmarcher *et al* 2007; Kodner 2009; McDonald *et al* 2007; Øvretveit 2011; Powell Davies *et al* 2006; Smith *et al* 2012; Tsai *et al* 2005

The nature of the evidence in support of effective care co-ordination provides a clear message that systemic and organisational changes alone are unlikely to be sufficient to drive greater care co-ordination at a clinical and service level, even if they provide a supportive framework (Ham *et al* 2013). As the box above suggests, however, there are a range of tools and strategies that may be deployed at the interface between care providers and service users. In practice, it appears that multi-component approaches have more success in meeting the goals of care co-ordination than those that rely on a single or more limited set of delivery strategies (Powell Davies *et al* 2006), yet the evidence for 'how to' deliver better care co-ordination remains relatively rare (Curry and Ham 2010). Hence, there is a general lack of knowledge about how best to apply (and combine) the various strategies and approaches to care co-ordination in practice.

Overview of the five care co-ordination programmes

In June 2012, with the support of an international panel of experts, The King's Fund selected five case study programmes from across the United Kingdom that had developed a track record in delivering effective care co-ordination for people with chronic or medically complex needs in primary and community care settings. Here, we provide a summary of the nature of each of these five programmes.

Midhurst Macmillan Community Specialist Palliative Care Service (England)

The Midhurst Macmillan service is a community-based, consultant-led, specialist palliative care programme in West Sussex, England, which covers approximately 150,000 people in a largely rural area across three counties. It is jointly funded by the National Health Service (NHS) and Macmillan Cancer Support, with a budget of around £1.2 million per year. The service enables patients with complex needs who are nearing the end of their lives to be cared for at home, and allows them to die in the place of their choosing. The Midhurst service caters for approximately one-quarter of all people needing end-of-life care in the area. Most patients on the caseload have been diagnosed with cancer, although there are an increasing number of referrals for patients with other conditions, including dementia and heart failure.

The service is run by a multidisciplinary team of nurses and palliative care consultants, occupational therapists and physiotherapists, as well as a large group of volunteers. Six staff – all clinical nurse specialists – act as care co-ordinators for patients. They are part of the multidisciplinary team and work in close co-operation with other care providers in the local area to provide palliative care in people's own homes. Other providers include general practitioners (GPs), district nurses, continuing care teams, and volunteers who are recruited and managed by Macmillan Cancer Support (Thiel *et al* 2013a).

Oxleas Advanced Dementia Service (England)

The Oxleas Advanced Dementia Service provides palliative care and support to enable people with advanced dementia to be cared for at home until their death. It covers the boroughs of Bexley, Bromley and Greenwich, in south London. Eligible patients must have a diagnosis of moderate to severe advanced dementia, with a range of complex mental and physical co-morbidities requiring social care input. A carer (usually a family member) must also be able and willing to care for them at home. Patients tend to be in the last year of their lives, with an average age of 75.

The service is led by an old age psychiatrist, with care co-ordination provided by an advanced practice nurse, community psychiatric nurse or a community matron who specialises in neurology, alongside a dementia social worker. The team has a specific focus on supporting carers to provide palliative care; it works closely with other care professionals, including occupational therapists, physiotherapists, community mental health teams and GPs (Sonola *et al* 2013a).

The Sandwell Esteem Team (England)

The Sandwell Esteem team, based in the West Midlands, is a holistic primary and community care-based approach designed to improve people's social, mental and physical health and wellbeing. The team provides care co-ordination for patients with minor to moderate mental health problems, co-morbidities and complex social needs in a community characterised by high levels of poverty and ill health, both physical and mental. The key aim is to prevent deterioration and admission to secondary care services. The team aims to empower patients to take control of their own lives by offering guided therapies and tools for self-help, as well as helping patients address their social problems by referring them to social and voluntary sector services such as debt advice agencies, abuse counselling services or housing agencies.

The team consists of care co-ordinators (link workers) and is managed by a clinical co-ordinator and support manager. It targets people on the severe mental illness (SMI) register and receives referrals from secondary, primary and community care organisations as well as social care and probation services. Patients can also self-refer. After an initial pilot phase of 18 months with assessments on a case-by-case basis, the service has begun to develop clear and binding referral criteria (Thiel *et al* 2013c).

Community virtual wards in south Devon and Torbay (England)

The community virtual wards based in GP practices in South Devon and Torbay CCG use a predictive risk model to identify patients at risk of admission to hospital, and proactively manage them through community-based multidisciplinary teams. Patients are admitted to the virtual wards on the basis of their risk score combined with assessments made by clinical staff familiar with their case. One of these clinicians also takes on the role of care co-ordinator. Patients are typically frail older people and/or those living with multiple long-term conditions and co-morbidities. During monthly team meetings attended by GPs, community and mental health staff, social workers and voluntary sector representatives, patients' level of risk is discussed and actions are proposed based on their physical and social care needs. The multidisciplinary teams also work with emergency and out-of-hours services to prevent unnecessary admissions to hospital. Co-ordination with the secondary sector and discharge liaison teams seeks to ensure that patients who are admitted to hospital can be discharged quickly back to the community (Sonola *et al* 2013b).

Community resource teams in Pembrokeshire (Wales)

Multidisciplinary community resource teams co-ordinate care for people with long-term illnesses, co-morbidities and frailty. The aim is to enable patients to remain in their homes for as long as possible and to avoid unnecessary hospital admissions.

The teams consist of community health care staff, social workers and voluntary sector representatives. There is also input from GPs and specialist nurses, although this varies from team to team. During weekly meetings, team members discuss patients they deem to be at high risk of hospital admission, and a care plan is developed to reduce this risk and improve the patients' health and wellbeing. Typically, the team member presenting the case will act as care co-ordinator. Patients can also be referred by a professional help desk, which accepts calls from individuals as well as from social workers and GPs. All of the teams have relationships with the secondary and acute sector to co-ordinate care planning when people are discharged from hospital into the community (Thiel *et al* 2013b).

Table 2: A comparison of the five programmes providing co-ordinated care in the United Kingdom

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
General description	**Consultant-led, community-based palliative care provision for terminally ill patients in their homes**	**Community-based specialist mental health and wellbeing services for people with mild to moderate mental health problems**	**Consultant-led, community-based home care for patients with advanced dementia**	**Community-based multidisciplinary teams co-ordinating care for older people**	**Community-based integration of health and social care services for complex case management**
Development stage	Well-established service embedded in the local health geography	Completed pilot stage, full integration into borough-wide health and wellbeing hub	Fully developed and embedded in local mental health trust	Virtual ward and predictive risk model fully developed and embedded in south Devon; recent introduction in Torbay (since October 2012). Continued work on predictive risk model to improve accuracy	Four teams have been operating since 2011 as part of a long-term plan to improve horizontal and vertical care co-ordination in Pembrokeshire; teams are still under development and the case study site is a work in progress
Objectives	Enable people to die in the place of their choosing. Avoid unnecessary hospital admissions. Improve quality of life at end of life	Improve health and mental health status of people with complex problems and improve wellbeing in the whole community	Avoid unnecessary accident and emergency (A&E) admissions and discharges to nursing homes; provide patients with care at place of their choosing; relieve carer's stress and improve patient's quality of life	Improve quality of care to users. Simplify access. Reduce number of assessments. Improve referral times. Improve independence. Reduce hospitalisations	Avoid unnecessary A&E admissions for patients with complex needs. Improve discharge from hospital. Improve social and health care co-ordination. Improve independence and quality of life
Dates	2007 to the present	2006 to the present	Greenwich: 2007 to the present; Bexley: 2011 to the present	2010 to the present	2011 to the present
Target population	Patients with complex diseases at the end of their lives in need of palliative care	Patients with complex mental health problems not engaging with secondary services and new cases identified by health practitioners or through self-referral	Patients with advanced stage dementia	Patients with complex health needs in need of intensive care and treatment that can be delivered at home with the right co-ordination	People with complex health and social care needs
Population coverage	All people with complex needs at the end of life in an area covering 19 GP practices (population 150,000)	All people in the Borough of Sandwell (population 309,000)	All people in Greenwich (population 255,500) and Bexley (population 232,800)	All people in GP practices in South Devon and Torbay CCG (population 289,000). Virtual wards should target the top 0.5% of the local population at risk of hospitalisation	All people living in the area covered by Pembrokeshire County Council (population 118,000)
Caseload	Around 400 per year	168 patients during pilot phase (2011/12)	Around 25 patients per year in Greenwich and 20 in Bexley	0.5% of each practice's weighted population – on average, 39 beds per virtual ward, ranging between 11 and 70	Between 50 and 80 depending on team size and geographic area
Funders	50% NHS funding, 50% Macmillan Cancer Support	Fully funded by local clinical commissioning group with some additional funding from local authority and third sector organisations	No specific funding; time needed for staff to make home visits is written into job descriptions	Funded by NHS England through use of incentive schemes targeted to improve quality of care in primary care	Joint funding by health and social care system in Wales

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Model type (organisational integration)					
Breadth of integration	Horizontal integration in a multidisciplinary team with elements of vertical integration through consultant input, and some connections to acute and tertiary services; strong links to primary care services (GPs, district nurses) but no full integration	Horizontal integration (multidisciplinary team); some vertical integration with a view to improving primary and secondary care co-ordination	Horizontal integration (multidisciplinary team) with view to expanding vertical integration by improving co-operation with hospitals and nursing homes	Horizontal (multidisciplinary teams); linkage to secondary and ambulance services, but no full integration	Near-complete horizontal integration within teams, with some pooled funding and resource use; elements of vertical integration with acute care
Degree of integration	Integrated provider model on community health level; co-ordinated model with other care providers and social care	Full integration within community and primary care; co-operation but not integration with social care	Greenwich: full integration of community and social work team, pooled budgets and management structures; Bexley: social worker is part of multidisciplinary team, but no integration of health and social care	Fully integrated provider model for team; co-ordinated model with other care providers	Integrated provider model on community health and social care level, including third sector organisations; low but increasing vertical integration with acute sector and GPs
Information management (functional integration)					
Use of shared electronic medical records	Only within the team. Reliance on face-to-face and telephone conversation to exchange information with primary care team as well as use of notebook at patient's home	Limited – integrated community health information, with data-sharing agreements with other providers and services (eg, probation). No integration with social services and GPs	Limited for both Greenwich and Bexley, even within teams, as mental health and community staff use different systems. Some staff can access social care information technology (IT) system and vice versa. Use of mobile phones, face-to-face and email communication	Limited – integrated community health and social care information system, with some provision for out-of-hours services; GP systems separate but accessible by health and social care co-ordinators in GP practices	A system is in place giving social and health care workers access to each other's records, but it is complex and slow and underused. Staff prefer and rely on face-to-face, telephone and email communication
Use of risk stratification	Informally through clinical assessment. No use of a tool	No	No	Yes – virtual wards use predictive risk modelling tool	No, although there are plans to introduce a tool
Providers (professional integration)					
Direct	Consultants, clinical nurse specialists, health care assistants, physiotherapists, occupational therapists	Care co-ordinators, counsellors, GPs, social workers, maternal mental health workers	Consultants, social workers, district nurses, clinical nurse specialists, care co-ordinators, community matrons	Care co-ordinators, community nurses, occupational therapists, physiotherapists, social workers, GPs, voluntary sector, district nurses, clinical nurse specialists	Social workers, district nurses, chronic conditions specialist nurses, physiotherapists, occupational therapists, resource managers, third sector organisations
Indirect	District nurses, GPs, home care, hospital-based consultants, hospices	Third sector organisations, local council, acute trusts, specialist care	Third sector organisations, home care, hospital-based consultants	Home care	GPs, acute sector hospitals, home care; plans to expand integration with GPs and acute sector

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Approach to care (service integration)					
Single point of referral	Yes – referrals from multiple sources	Yes – one central hub, but the team also accepts direct referrals from probation and maternal health services	Yes – referrals from multiple sources	Yes – cases identified through risk stratification tool, in some instances by team members	Yes – social care has one central hub, but team members refer patients at the meetings
Eligibility criteria	Yes – people at end of life with complex needs	No – although criteria are now being developed	Yes – advanced dementia scale	Yes – as identified by risk assessment tool	No – although criteria are now being developed
Single assessment	Yes	Yes	Yes	Yes	Yes
Care planning	Yes	Yes, but strong ad-hoc element	Yes, but strong ad-hoc element	Yes	Yes, but informal; in process of being formalised
Care co-ordinator or case manager	Case manager	Care co-ordinator	Care co-ordinator	Case manager	Care co-ordinator
Multidisciplinary team	Yes	Yes	Yes	Yes	Yes
Use of financial incentives	No	Yes	No	Yes	Yes
Use of non-financial incentives	No	Yes – GP engagement through peer pressure and mental health training	No	Yes – GP engagement through peer pressure	Yes – GP engagement through peer pressure
Engaged users (personal integration)					
Self-management support	Yes – but limited due to patient's status (at end of life)	Yes – very strong element delivered throughout the programme	Yes – but limited due to patient's advanced condition	Yes – on low level through voluntary organisations and care co-ordinators	Yes – through voluntary organisations
Focus on supporting informal carers	Limited – carer assessment and bereavement support	Yes	Yes	Yes – by care co-ordinators and voluntary sector	Yes – through voluntary sector support
Other components					
Voluntary sector broker	Yes	Yes	No	Yes	Yes
Peer support	No	Yes	No	No	No
Elements of co-production	Yes – patient and carer feedback lead to organisational service adjustments	Yes – active involvement of patients and former patients in design of services	No	No	No
Carer assessment and support	Yes – part of patient assessment	Yes – identification and registration of carers, referral to support services	Yes – identify carers' needs on case-by-case basis and offer/organise support	Yes – carer registration and support from voluntary sector	Yes – assessment of carers' needs is a routine part of patient assessment in Wales

Table 2: (continued)

	Midhurst Macmillan Palliative Care Service	Sandwell Esteem Team	Oxleas Advanced Dementia Service	South Devon and Torbay virtual wards	Pembrokeshire community resource teams
Results					
User and professional experiences	Patients and carers feel supported and less anxious; staff have high satisfaction levels	Patients and carers feel supported and empowered; staff have high satisfaction levels	Patients and carers feel supported and less anxious; staff have high satisfaction levels	Increased staff motivation and positive evaluations from GPs	Team mostly positive about the approach, but some dissatisfaction about workload and lack of funding
Care outcomes	High levels (>90%) of enabling patients to die in place of choosing; lower A&E admissions compared with hospice care	25 patients on SMI register improved and discharged from register; statistically significant improvement on clinical and wellbeing scales (with no control for regression to the mean)	Improved quality of life scores for patients and carers	Improved care co-ordination resulting in shorter waits and improved independence (not yet formally evaluated)	Not yet known, although anecdotal evidence suggests improved patient satisfaction
Utilisation of services	Reduced A&E admissions and number of deaths in institutional settings	Some data suggests that secondary care use is declining, although methodologically difficult to attribute to Esteem Team and Sandwell hub	Patient audit of 2009 suggests fewer than expected A&E admissions and residential care admissions for patients involved in the service	Fewer residential home placements. Initial reduction in A&E admissions and length of stay has not been sustained over time	2012/13 results: reduction in admission rates for chronic obstructive pulmonary disease (COPD) patients. Below-average length of stay for diabetes, COPD and coronary heart disease (CHD) patients compared with local health board averages. Almost has the continually lowest delayed hospital discharge percentages of all areas covered by the health board
Cost-effectiveness	Lower cost of care for patients in last 12 months of life compared with hospice care, as early referral into the service can prevent A&E admissions	Improved system performance by efficient use of allocated budget	Reduced costs to NHS and social care commissioners	Improved quality of care at no extra cost	Evaluation of cost still ongoing; indications of reduced care costs through improved care co-ordination

Approaches to care co-ordination: a comparative analysis

Aims and objectives

As Table 2 illustrates, there are a number of similarities and differences in the approaches adopted by each programme to support people with complex health and social care needs in their communities. In terms of the key aims and objectives, all five case study programmes share a common goal: making a positive difference to the quality of life of service users through improving people's mental and physical wellbeing. In all cases, this objective has been linked to measurable care outcomes such as: enabling people to die in the place of their own choosing (Midhurst); improving mood (Sandwell); relieving carer stress (Midhurst and Oxleas); and enabling greater functional independence (south Devon and Pembrokeshire). The primary focus, however, has been to examine the holistic needs of service users and identify how they can be supported to manage their complex needs and have a better quality of life. This is consistent with evidence which suggests that the more successful approaches to managing patients with co-morbidities in primary and community care should focus on promoting functional independence rather than disease management (Smith *et al* 2012).

Avoiding or reducing unnecessary hospital admissions and promoting home-based care as an alternative to care provided in institutional settings was also characteristic of all the sites (except Sandwell). However, none of the programmes set a specific target to reduce or contain costs. While this was implicit to their work, it appears that care co-ordination has been taken forward primarily as a quality improvement strategy rather than one designed to contain costs. Indeed, while most of the case study programmes were able to demonstrate quality improvements, they could demonstrate only a marginal impact on costs (*see* below).

Target populations

Effective targeting of service users has often been cited as an essential feature of integrated care strategies (eg, Kodner 2009; Ross *et al* 2011). Taking a population management approach (as opposed to carve-out disease management strategies) that is designed to look holistically at the priority needs of local communities tends to produce better results for patients (eg, Ham 2010). Both of these elements were common features across the five case study programmes; services were made available to all people across a defined geographic area, but then targeted to those in most need, often using explicit inclusion criteria.

Another core feature of the five care co-ordination programmes is that each tended to be specifically targeted at local communities or neighbourhoods (no more than 30,000 people on average). This approach not only enabled case managers and/or care co-ordinators, together with multidisciplinary teams, to work with manageable caseloads, but also enabled care co-ordination teams to establish close working relationships with other care providers, members of the local community, and patients and carers.

Many staff from the five programmes stressed the importance of building community awareness of and trust in the model of care they had developed – for example, to ensure referrals and to support effective face-to-face communication (*see* 'Information management', p17). Across larger geographic areas, such as in south Devon and Torbay or Pembrokeshire, a number of multidisciplinary teams have been created to ensure that each programme has a locality focus.

Organisational development

Another key characteristic of the five programmes is that each underwent a developmental phase or piloting process, often with specifically allocated but time-limited funds. The developmental histories for each case study programme describe a process through which their innovations have survived, adapted and grown, despite the feeling that they were often regarded as 'outside the system' and lacking some legitimacy. Nonetheless, most programmes now describe their approach as 'embedded' – ie, it has become an accepted way of working within their local health economy – an achievement that can take at least six to seven years.

It has often been said that innovations in integrated care need to be given considerable time to 'bed down' as organisational models before they can achieve their objectives (Goodwin *et al* 2012) and that there is a maturity model at play in the life-cycle of their development (RAND Europe and Ernst & Young 2012). While this research appears to support these assertions, two further observations need to be made. First, most respondents from the five case study sites felt that their programmes were in a continuous state of change that needed constant nurturing. Second, the feeling of being 'outside the system' has remained manifest, with staff feeling vulnerable to changes in service and funding priorities. The most stable programme appears to be in South Devon and Torbay CCG, where health and social care commissioners had joined forces to actively lead and promote integrated models of care, allowing them to develop over time.

Organisational model

All five case study sites had sought to develop strategies of 'horizontal integration' across local communities based on the creation of multidisciplinary teams drawn from a range of health and social care agencies. The range of members within these core teams appears to demonstrate the importance of a diverse yet 'dense' community-based network of professionals working closely together. However, there appears to be an exception, in that local general practitioners (GPs) are not often central to the care co-ordination process and have varying degrees of engagement both within and across the case study sites.

This lack of engagement from GPs represents a curious paradox, as one of their core roles is to provide continuity of care to local people and act as the patient's advocate through referrals to other services. This phenomenon does not appear to be limited to the United Kingdom; possible reasons for it include (after Goodwin *et al* forthcoming):

■ GPs' preference to work as independent practitioners

■ a payment model that places the work of GPs outside the wider health and social care system

■ the lack of time to get involved in care planning (for example), given intense workloads

■ lack of sufficient remuneration for the work involved.

As a result, success in fostering relationships with GPs varied greatly across the five case study sites. GPs had the strongest involvement in south Devon and Torbay, where the virtual wards are hosted by each GP practice, placing GPs at the heart of the model; direct

financial incentives for GPs and practice staff also mean they are fully involved in the care co-ordination process. In contrast, the Oxleas model is hosted by a secondary care provider, distancing professionals from GP practices and making it more difficult for specialist nurses and community matrons to develop strong links to primary care. Positioning and remuneration, then, seem crucial when it comes to engaging GPs in care co-ordination.

While the multidisciplinary teams in each programme had moved in the direction of becoming fully integrated community-based models of care – some with separate funding and governance arrangements – the degree of 'vertical integration' with hospitals appears to have remained weak. At best, the case study sites had managed to create 'linkages' – for example, with key clinicians to share information and/or raise awareness, or to develop strategies to avoid unnecessary hospital admissions and to secure early discharge – but all sites reported this as under-developed and cited the need to develop better relationships with hospitals, especially when managing effective care transitions from hospital to home.

Funding

One of the areas where there was little commonality was in the way co-ordinated care programmes were being funded. Indeed, the funding histories across the five sites show how programme leaders have had to take an entrepreneurial approach to finding resources to support their innovations, particularly in the early stages. Two sites (south Devon and Pembrokeshire) had become 'fully funded' by joint health and social care commissioners, who also played an important role in leading and promoting the programmes. In Sandwell, resources have been pulled in from a range of different funding streams controlled by local clinical commissioning groups, but with additional funding drawn from a range of sources, including the local authority and third sector organisations. In Midhurst, 50 per cent of the programme costs each year have been supported by the Macmillan Cancer Support charity, with the remainder drawn from local clinical commissioning groups. In Oxleas, resources for the programme have been secured from internal funding within the trust.

Of all the challenges faced by the five care co-ordination programmes, funding was most often cited as the greatest concern. This was particularly the case in three areas – Oxleas, Midhurst and Sandwell – where their financial sustainability was reliant on multiple funding sources that were not guaranteed to be available in future years. For example, in Midhurst, there had been discussions about phasing out the charitable element to the programme's funding. In Oxleas, future funding for staff remained unclear due to limited overall resources in the trust, and potentially differing priorities. Prospects for longer-term funding seemed more stable in south Devon and Pembrokeshire, where support from a single commissioner using pooled health and social care funds was available; but even here, the wider context of a squeeze on public sector budgets has brought doubts about future levels of investment. As a result, all programmes felt somewhat 'at risk' financially, although this was clearly a more pressing problem among those with multiple sources of funding.

Approach to care

A common approach across the five case study programmes was to encourage referrals from multiple sources, often including patients and family (*see* 'Engaged communities', p18). To overcome the potential challenges of managing such a process, and the additional costs implied, all programmes developed a single point of entry through which new referrals would be managed. All programmes then filtered cases through to their multidisciplinary teams to undertake case reviews, initiate assessments and develop care packages. The ability to generate referrals from multiple sources was seen as a key aspect of success – for example, in Sandwell and Midhurst, this meant support could be provided to people before they experienced a crisis (and so avoiding unnecessary hospital admissions, for instance).

All five programmes had an explicit focus on supporting people to live at home and used multidisciplinary and community-based teams as a means to achieve that. The teams typically utilised the skills of specialist nurses, primary care professionals, social care staff, allied health professionals and the voluntary sector, to conduct holistic assessments which take health and social care needs into account. None of the programmes had a pre-defined care package; they preferred instead to draw on all resources available locally to tailor care directly to the needs of individual service users. A care co-ordinator acts as a single point of contact and works with the patient, their carer(s) and the multidisciplinary team to develop a care plan. Once this has been agreed, the co-ordinators work with the team, the patient, the patient's family and other care providers to deliver co-ordinated and coherent care. Personal continuity of care is actively encouraged, and the care teams work hard to ensure an immediate response to care needs as they arise.

Care co-ordinators

The role of the care co-ordinator appears to have been crucial in enabling the programmes to deliver their objectives effectively. In other words, co-ordinating care around the needs of patients and carers requires a dedicated staff member to facilitate the process. However, the role of care co-ordinator is far more than simply navigating people between care providers. The care co-ordinator role is multi-faceted, and includes:

- providing personal continuity of care to the patient/carer, acting as a key point of contact for care

- being the patient's advocate in navigating across multiple services and settings

- providing care directly in the home environment (by case managers with advanced skills)

- ensuring that professionals within the multidisciplinary team are kept informed of the patient/carer's situation

- taking accountability for the provision of care and ensuring that care packages are put in place and delivered

- communicating with the wider network of providers (outside of the core multidisciplinary team) so that information about the patient/carer is shared and any actions required are followed up.

These key functions of the care co-ordinator were consistent across the five programmes despite differences in the nature of the patient group being served and whether they were located in rural or urban settings, affluent or deprived communities, or dealing with smaller or larger caseloads. However, the type of person undertaking the care co-ordination function varied greatly. Most care co-ordinators had been community or specialist nurses, yet the role has also been taken on by non-clinical 'link workers' (in Sandwell) and health and social care co-ordinators (in Torbay). There appears to be a continuum from the non-clinical approach – primarily providing personal continuity to service users and acting as their advocate to ensure that care is co-ordinated around their needs – to the clinical approach, in which a case manager would also be able to provide clinical care directly (*see also* Goodwin *et al* forthcoming).

None of the care co-ordinators had received any specialist training for the role, but all reported having good 'people skills' and in-depth knowledge about the local community. Most had lived and worked in their community for several years, acquiring a good understanding of the local health or social care system, which helped them to support patients in negotiating between care providers. Building effective working relationships between care co-ordinators, multidisciplinary teams and wider service providers has been important in supporting better co-ordination.

Team culture

Feedback from programme participants combined with observational analysis revealed that all five of the programmes placed considerable emphasis on team-building and networking within the core multidisciplinary teams providing care. It was commonly reported that building a supportive team culture did not happen in a vacuum; it required continual nurturing over time to reinforce the shared vision and personal commitments needed to enable the programmes to succeed. Indeed, one characteristic underpinning the success of each case study programme was the personal commitment demonstrated by staff – both managers and professionals – to go that 'extra mile' by working beyond the boundaries of their job description in order to achieve the best results for their patients, and in supporting colleagues to do the same. We found a range of explicit strategies that promoted a strong ethos among staff to 'do the right thing' – for example: promoting the needs of patients before their own needs; supporting knowledge-sharing; and enabling role substitution through staff empowerment.

Developing a collaborative culture has often been put forward as a key ingredient of integrated care. What was striking in our research was the consistent emphasis placed on 'creating energy for change' through an ability to build social capital and promote engagement and learning between partners in care across the local community. This took considerable time and effort and sometimes meant that progress was slow as a result; yet it was also recognised as a necessary process and catalyst for change.

Information management

Approaches to information management varied widely, but the lack of access to shared electronic health records was a common issue. In all sites, it was reported that a significant amount of time and effort had, therefore, to be placed on interpersonal communication between members of the multidisciplinary team, but also with other care providers such as GPs. Strategies included face-to-face meetings, ensuring telephone or email follow-ups, and creating joint records through notes left at patients' homes. All of these strategies were witnessed – for example, in the Midhurst programme, where responsibility for keeping everyone informed was taken forward by the clinical nurse specialists acting as the patient's care co-ordinator. This included attending regular meetings in each GP practice to report back on patient care and to seek input and advice from all team members. In all five programmes, the regular multidisciplinary team meeting was the hub of communication and knowledge exchange, where specific cases (current and new) were discussed.

This 'low-tech, high-touch' approach was viewed by professionals as both a challenge to be overcome but also as an asset to be retained. All sites reported that the effectiveness of decision-making and communication could be significantly improved through access to shared health care records and better technology. The process of checking records on separate health and social care systems, for example, was seen as onerous, and keeping all partners well informed of a patient's situation was highly time-consuming. However, it was commonly reported that there was great value to this level of face-to-face communication with colleagues as a way of building trust, fostering collaboration and having more meaningful conversations about the needs of patients with complex conditions. Hence, information technology (IT) was seen as a potential tool to improve communication, but personal interactions remained essential.

In the absence of data to support risk stratification, developing community awareness and vibrant networks of communication between partners in care and the community has enabled co-ordinated care teams to get earlier warning of people in need of care who might otherwise have fallen into crisis. Such networking, for example, was reported as being particularly important in identifying people nearing the end of life and referring them to Midhurst, and so helping to support them at home without the need for

hospitalisation. In Sandwell, strong community-based networks have enabled earlier referrals from people with mental health needs who would not otherwise have been supported. Hence, while the lack of integrated medical records was seen as a potential disadvantage, the case study programmes placed great importance on networking strategies to ensure effective communication about the needs of service users.

Engaged users

Without exception, all five programmes sought to promote engagement with service users and their informal carers or family members. Indeed, all had developed explicit strategies and tools to support self-management, with a specific emphasis on undertaking carer and family assessments on which to build a range of support packages to meet each patient's needs. For patients with complex needs, especially those nearing the end of life (Midhurst and Oxleas), building resilience among carers to cope with supporting the long-term management of patients at home has been a key strategy. All sites were aware that shifting care for patients with complex needs into the home environment would place added burdens and responsibilities on carers; focusing on the needs of carers directly has therefore proven to be effective in helping to alleviate stress and anxiety, resulting in positive views about the programmes among patients and their carers. This approach typically included bereavement support and counselling after death. However, there was less evidence within the sites of shared decision-making with patients and carers (for example, during care planning).

Engaged communities

Community engagement, incorporating the voluntary sector, has also proved central to what the five case study programmes have been able to achieve. In Midhurst, Pembrokeshire and south Devon (but not yet in Torbay), the voluntary sector has been brought into the core multidisciplinary team. In south Devon and Pembrokeshire, volunteer 'brokers' attend team meetings, taking part in the discussion of cases and development of care plans; while in Midhurst, the volunteer co-ordinator plays the same role and uses this information to identify and deploy volunteers matched to individual patients. In Sandwell, community groups are engaged as partners in care and many members of the community (including previous service users) have taken on specific support roles. In addition to utilising volunteers within the care programmes, all sites placed a premium on building community awareness and trust with local populations as a strategy to ensure that people knew their services were available and would therefore be more likely to recommend and signpost friends and family to the programmes.

Evaluation of impact

The five care co-ordination programmes were selected in an open competition to be part of the case study research (*see* Appendix A). A key criterion for selection was that each had to have been able to demonstrate evidence of a positive impact on one or more (but preferably all) of the following: patient experiences, care outcomes and cost-effectiveness. However, the results of the application process revealed a chronic lack of attention to demonstrating and measuring outcomes. Few programmes used patient feedback proactively to reflect on care services provided; information on care outcomes was not routinely collected; and changes to the utilisation and costs of services have been rudimentary (Goodwin 2012).

The business of monitoring and measuring outcomes on care co-ordination therefore does not appear to be strongly valued (culturally or managerially) in the National Health Service (NHS) as a way of judging performance. It should be stressed that this problem is not just confined to the NHS and the United Kingdom; international studies have also shown this to be a problem, especially in publicly funded health systems (Goodwin *et al* forthcoming). This lack of evidence for care co-ordination is a key reason why there are relatively few

demonstrable examples of success (Ham and Walsh 2013) and may partly explain why such innovations often fail to progress past the pilot phase into mainstream thinking and practice (Goodwin *et al* 2012).

However, all five case study programmes were in the process of developing robust methods to demonstrate impact, though none had actively developed such strategies from the outset. As Table 2 (on p12) shows, all the sites were able to provide some evidence to support the beneficial impact of their programmes. However, the quality and robustness of this evidence can best be described as weak, with only one programme (Midhurst) having conducted an independent evaluation (Thiel *et al* 2013a).

When reviewing impact data from the five sites, one of the key concerns was the methodological weaknesses that affected whether improvements could be directly ascribed to each programme's work. For example, statistically significant improvements in the mental health of patients in Sandwell may have been the result of 'regression to the mean' rather than the direct efforts of the Esteem Team to improve clinical outcomes. Similarly, reduction in hospital admissions for patients with chronic obstructive pulmonary disease (COPD) in Pembrokeshire over one year may have been random, so attributing outcomes directly to the work of the community resource teams is problematic.

A common objective across all the care co-ordination programmes has been to support people to live at home to avoid unnecessary hospitalisation. Yet it is difficult to ascertain how many hospital admissions may have been avoided. Apart from Midhurst, no site has carried out a study comparing outcomes for their patient population with a group that did not receive the intervention.

Supporting an evaluation study with control groups was seen as too expensive or too time-consuming for most programmes to contemplate. In terms of patient and carer experiences, most case study sites had undertaken some kind of investigation in the form of questionnaires, focus groups or narrative case studies. However, no quantitative evidence was available, either because the sites had not carried out large-scale surveys or because their approach was at a relatively early stage.

The lack of robust evidence on cost-effectiveness and the problems related to attribution are common problems in this field. Recent evaluations of 16 integrated care pilots and 30 integrated community care projects in the United Kingdom have identified similar methodological difficulties (Bardsley *et al* 2013; RAND Europe and Ernst & Young 2012). Nonetheless, despite these methodological constraints, the overall evidence across the five case study programmes suggests that it is legitimate to claim that care co-ordination can improve the quality and experience of care for patients with complex conditions without adding to overall system costs. However, the likelihood of care co-ordination being able to generate significant cost savings is low when delivered at the scale on which the five case study programmes were operating. Given that none of them had an explicit objective to generate financial savings, the strategy they have followed can best be described as one of quality improvement rather than cost reduction. The inability to demonstrate cost-effectiveness, however, is a weakness that may have negative consequences given the tentative nature of ongoing funding.

Building care co-ordination programmes: key challenges and facilitators

Key challenges

It takes time to build an effective programme of care co-ordination, and the history of the five case study sites reveals that this path has not been easy. A number of common challenges emerged, and fundamental to these is the fact that care co-ordination programmes have been developed within systems of care that do not treat such innovation as 'core business'. Silo-based thinking and existing medical paradigms have perhaps been the greatest challenges at the clinical and service level. In Midhurst and Oxleas, for example, both programmes needed to convince other care professionals – particularly specialists – that it was possible to provide palliative care in people's own homes, without the need for hospital beds.

There was often strong reluctance to refer patients to programmes that were seen as outside existing professional norms and values, which is why all five sites emphasised the need to 'win hearts and minds' to ensure that their service was accepted and used. All programmes reported making huge efforts to ensure effective communication between partners in care, with most heavily reliant on face-to-face communication, email exchanges (where permissible) and telephone conversations. The lack of integrated information technology (IT) systems to better support information exchange has proved to be a major challenge for all sites due to the incompatibility of existing health and social care IT systems; as a result, the time burden related to communication has been heavy.

Funding has been, and remains, a significant concern. As discussed in the comparative analysis above, a key challenge to the future of the programmes has been the ability to find longer-term and more secure resources. This has been a particular problem where funding has had to be drawn from multiple sources on a time-limited basis, increasing the complexity of relationships across different funders as well as adding to the feeling of being 'at risk'. In contrast, having a single source of funding, as in the commissioner-led schemes in south Devon and Pembrokeshire, has enabled a greater degree of stability. Yet even where funding has been secured for the long term, it is often seen as insufficient to increase staffing levels, fund enhancements, and meet ever-increasing demands from patients.

All sites agreed that the lack of general practitioner (GP) engagement had contributed to slower than anticipated progress, in terms of the ability both to provide effective care co-ordination and to ensure referrals into their programmes. A variety of strategies to improve GP engagement have been used – for example, financial incentives, information sessions and attending regular GP meetings. However, none of the programmes had yet achieved the desired level of engagement with GPs other than in south Devon, where virtual wards were hosted by GP practices.

A final key challenge identified by the case study programmes was the provision of effective care co-ordination for people living in remote and rural locations. Providing home-based care that can respond quickly to people's needs appears to be a hallmark of the strategies developed to support people with complex needs; yet rurality and its associated challenges (covering long distances, which reduces capacity and increases costs) has presented particular problems for the case study programmes. In both south Devon and Pembrokeshire, interviewees remarked how it was far more difficult in remote locations to identify complex cases earlier and so help prevent deterioration through packages of care support.

Key facilitators

While staff involved in the programmes often described having to think laterally to work around existing regulatory and organisational rules in order to establish their programmes, there was a sense that each had benefited from a supportive political narrative that actively encouraged the development of person-centred care co-ordination. Indeed, depending on the nature of the patient group, programme leaders used the leverage contained in best practice guidance to justify continued funding and support. For example, the Sandwell Esteem Team was helped by policies seeking to increase access to psychological therapies (IAPT), while in Oxleas, the programme was supported by a national strategy to improve diagnosis and treatment of dementia patients in primary and secondary care. National efforts to improve end-of-life care and to enable people to die in a place of their choosing had also given added credibility to the Midhurst programme.

Consistent with other experiences where integrated care has been effectively implemented (eg, Ham and Walsh 2013), local leadership and commitment have been essential ingredients. In each of the case study programmes, interviewees identified between one and three key leaders responsible for the successful development and operation of their programmes. These people's dedication to improving services for patients and their ability to not be limited by the status quo was seen as essential for initiating the programmes and challenging perceived wisdom about how care can best be provided. Long-term association with the programmes was also seen as essential in providing the 'leadership continuity' required to drive through innovation and change.

Closely related to the dedication of key staff was the development of a clear joint vision for how better patient care could be achieved. All interviewees agreed that success hinged on ensuring that this vision was shared by all stakeholders (staff, external organisations, patients and carers, voluntary sector organisations, etc); indeed, many interviewees pointed to the fact that present-day problems in care delivery could be traced to a past lack of engagement with, or by, a particular group of stakeholders.

A key feature accounting for the success achieved by all five programmes has been their ability to react flexibly to the changing needs of patients. There are no pre-defined care packages; care plans are developed together with patients and carers and are tailored to meet their needs. The ability to react in real time to sudden changes in a patient's condition was seen as crucial for patients with complex needs, whose health status can deteriorate quickly and for whom the progress of their illness can be unpredictable. The programmes used a range of strategies that promoted a strong ethos among staff to 'do the right thing' – example: promoting the needs of patients before themselves; supporting knowledge-sharing; and enabling role substitution and subsidiarity through staff empowerment. Allowing professionals to 'use common sense' (specifically for non-clinical care) meant that many had undertaken tasks that may not be strictly related to their professional roles, but have resulted in faster and appropriate intervention for the patient.

Finally, a critical component of care co-ordination for people with complex needs is the unpaid support provided to patients by informal carers, family and volunteers from the local community. The ability to support people to live at home, or to ensure that an effective 'early warning' system is in place before they fall into crisis, requires 24/7 support that cannot be provided by the limited resources available to health and social care teams. This seems especially important for highly vulnerable patients nearing the end of life. Experiences from the Midhurst Macmillan Service and Oxleas Advanced Dementia Service show the central importance of family members and volunteers in fulfilling such roles. Both programmes have invested in building the resilience of carers to support patients at home and in engaging with the wider community to provide a range of essential 'low-level' support services that help people remain independent and at home for longer.

Conclusions

The purpose of this report has been to uncover the key lessons and markers for success in how care co-ordination might be effectively transferred between different contexts and settings. Findings from our research into five UK-based case study programmes suggest that there are a number of transferable lessons in how to approach care co-ordination for people with complex needs at a clinical and service level; yet the success of such approaches can be significantly influenced by the contexts within which programmes operate. Hence, a multi-level analysis has been provided here to describe the key success factors in building and delivering an effective programme of care co-ordination.

Personal level

- Care co-ordination for people with complex needs requires a holistic focus on the needs of both patients and carers.

- Explicit strategies are required that promote engagement with service users, particularly to promote self-management through a range of support packages that meet their needs.

- Approaches appear to be more effective where they focus on promoting functional independence and wellbeing, enabling people to cope and live well with their conditions rather than a purely clinical focus on managing or treating medical symptoms.

- Building resilience among carers is important in the promotion of home-based care and can be effective in alleviating stress and anxiety.

- Relational continuity of care with named care co-ordinators is highly valued and, by having just one person to call, can enable real-time issues to be dealt with more effectively.

Clinical and service levels

- Supporting referrals from multiple sources, including directly from those living in the community, can enable professionals to put services in place before crises occur.

- Having a single point of entry helps co-ordinate these referrals more effectively and provides a single contact point for patients and carers.

- The role of the care co-ordinator appears to be crucial in supporting the management of referrals and enabling programmes to deliver their objectives effectively.

- The care co-ordinator role is flexible and multi-faceted, and can include:

  - managing referrals

  - providing personal continuity of care to the patient/carer and taking accountability to ensure that care packages are put in place and delivered

  - being the patient's advocate in ensuring that professionals within the multidisciplinary team are kept informed of the patient/carer's situation

  - providing care directly in the home environment

- communicating with the wider network of providers (outside of the core multidisciplinary team) so that information about the patient/carer is shared and that any actions required are followed up

- helping patients to navigate across multiple services and settings.

■ Care co-ordinators need to be imbued with responsibility and power to exert influence within the local health system. Without this they can become isolated, demoralised and ineffective.

■ A comprehensive and holistic health and social care assessment, including that of carers' needs, is necessary to enable the development of a personalised care plan.

■ Care plans need to be tailored directly to the specific needs of individual service users. No defined care packages are set in advance and service provision is geared to providing a flexible response to patients as their care needs change over time.

■ Multidisciplinary teams, working to a common set of objectives and priorities that bring together a range of specialist and generalist skills, effectively combine to support people to live well at home.

■ Team-building is important, focusing on reinforcing a shared vision and personal commitment from staff to achieve the best outcomes for patients.

■ Flexibility within the care team is essential, supported by approaches that enable role substitution through staff empowerment.

Community level
■ The role of volunteers and third sector organisations in supporting the needs of patients and carers gives important added value to care co-ordination programmes – for example, through the role of a volunteer 'broker'.

■ The role of the community should be seen as integral to the care-giving process and, where appropriate, this role should be formalised into supporting the work of the multidisciplinary teams.

■ Building community awareness and trust with local populations and other care providers can give greater legitimacy to new approaches to care. This can increase the likelihood of referrals into a programme, enabling people in need of care to be identified and cared for earlier, thereby potentially avoiding a crisis.

Functional level (information management and communication)
■ A significant amount of effort is required to ensure effective communication between members of the multidisciplinary team, and also with other care providers involved in patient care.

■ Access to shared electronic health records would add significant value to the ability to share information, but it is not an essential attribute of well-performing approaches to care co-ordination.

■ A 'high-touch, low-tech' approach has value in promoting face-to-face communication, fostering collaboration and enabling meaningful conversations about the needs of patients with complex conditions.

Organisational level
■ A population management approach is required to holistically examine the needs and priorities of a defined geographic population.

■ Effective targeting of service users is required to prioritise care provision, supported where possible by the intelligent use of data to enable risk prediction.

- Programmes of care co-ordination need to be localised so that they concentrate on specific communities and neighbourhoods. Larger populations will require a range of locality-based programmes operating together.

- Local leadership and long-term commitment – from commissioners and providers – are important for the successful development of care co-ordination programmes in practice.

- Early on in programme development, partners in care should develop a shared vision and shared understanding about how the care process should be changed to better support patients. Challenging silo-based thinking and overcoming structural and funding constraints first requires a shared agreement on the need to change and how this might best be achieved.

System level

- Programmes of care co-ordination in the United Kingdom have developed within a fragmented overall system of care that has limited their potential to become embedded and accepted as new ways of working.

- Having a single source of funding from an integrated health and social care commissioner can support longer-term strategies and provide a greater degree of stability.

- A political narrative that supports innovation in person-centred care co-ordination has provided much-needed credibility and support.

Key observations

Programmes of care co-ordination, like those investigated in this research, take many years to grow from development projects into more mature models of care. However, the process of programme development does not appear to reach an 'end point'; and new approaches that lie at the margins of what might be regarded as 'core business' appear to remain somewhat 'at risk', since their future is not guaranteed. Consequently, success in care co-ordination appears to be the result of a long-term process, facilitated by key local leaders, during which the capability and legitimacy of new ways of working is built up over time (at least six to seven years in the context of this study).

A common observation by the key leaders in each programme was that 'there was no substitute for going through the process of development' since so much of their success was built on forging and nurturing alliances. Hence, a key lesson is that different approaches to care co-ordination have highly context-specific histories and cannot be transported 'en bloc' from one location to another. Achieving effective programmes of care co-ordination requires a bottom-up process to develop the building blocks for effective partnership working, rather than introducing new top-down models of care, no matter how well they may have worked in other settings. Understanding the local context, then, is the key to transferring lessons from other programmes of care co-ordination.

Another key lesson is related to the degree of realism that is required when it comes to estimating the impact that care co-ordination might have on costs. It has often been assumed that care co-ordination for the most 'at-risk' groups, particularly in the form of intensive case management, can reduce hospitalisations and therefore save money (Ross *et al* 2011). However, while all of the programmes of care co-ordination that we examined were able to demonstrate improvements in care experiences and outcomes, impact on reducing costs and improving cost-effectiveness was limited. This suggests that managers and policy-makers need to be realistic about the potential financial impact of care co-ordination, and view the approach primarily as a quality improvement strategy rather than one specifically aimed at cost reduction.

The experience of the five UK-based care co-ordination programmes tells us that their approach largely remains 'outside' of the way care systems have traditionally operated. This means they have found it difficult to progress certain innovations and/or to do so relatively quickly. Of concern to all programmes was the apparent disengagement of general practitioners (GPs), which sometimes made effective information exchange difficult and prevented them from bringing the GPs' general knowledge of the patient/family into discussions about their care. Similarly, links with secondary providers have remained under-developed – for example, in securing faster access to specialist knowledge in the care process and ensuring better quality transitions from hospital to home. The latter point is important given growing evidence from the United States that a strong focus on care transitions can help reduce readmission rates (eg, Jackson *et al* 2013).

Hence, all five case study programmes recognised that progress would have been easier if they were operating in a more integrated delivery system – for example, where purchasing, planning, organisation and governance practices were more closely aligned. In the United States, the fact that care co-ordination models have tended to flourish within different 'integrated delivery systems' of care tells us that a supportive operating environment is important. Of the five UK-based programmes examined in this research, there was some evidence to suggest that there were advantages to having more 'fully integrated' provider teams working closely with a single health and social care commissioner.

Nonetheless, even where care programmes were operating within a more integrated delivery system, there were still significant challenges – for example, in making the case for continued or increased funding to build capacity and invest in new ways of working. To this end, the apparent lack of strategic attention to demonstrating impact in terms of care outcomes and/or costs remains a fundamental deficiency. Far greater attention is required to measure and reflect on performance, not only to justify levels of investment but also to reflect objectively on the quality of care being provided.

The characteristics of the five UK-based programmes of care co-ordination reinforce much of what was known about the components of successful approaches to integrated care (*see* Table 1, p 2). However, several key elements detailed in previous literature were not present in most of the sites, suggesting that these components are perhaps not so critical for successful care co-ordination. For example, single or shared clinical records were not evident in the programmes (except in Torbay, where social and community care teams can share data) and there was no evidence of continuous/remote patient monitoring; there were no formal discharge/transfer agreements (except in Pembrokeshire, where joint discharge and community teams based in the local hospital work with community resource teams); and there were no inter-professional networks to promote education and learning. Specific decision support tools, care guidelines and protocols were also not commonly used (except in Midhurst) and there was an absence of defined care packages. It might be concluded that dealing with patients with complex needs means that it is inappropriate to develop a protocol-driven approach, since care pathways are unpredictable (ie, there is no such thing as 'usual care') and greater flexibility in service response is required. However, it might also be the case that such approaches are less developed in the UK context. Either way, achieving success in care co-ordination does not appear to have been hindered in their absence.

One of the more problematic questions for the future is whether and how small-scale programmes of care co-ordination can be scaled up. This is a particular concern given the limited impact demonstrated by the case study programmes on cost-effectiveness. Yet this research suggests limits to the scale of operations at the service level, because the process appears to flourish at the neighbourhood level, where the benefits of close engagement with local communities sit alongside the need to have good working relationships within

multidisciplinary care teams dealing with manageable caseloads. However, lessons from south Devon and Torbay suggest that it is possible to scale up through building a number of locality-based approaches to care under the direction of an umbrella organisation. Yet in each case, the process of relationship-building takes time and, as in Pembrokeshire, is likely to lead to variable approaches to care in local contexts that may or may not be as successful.

As a final observation, it is clear that building effective programmes of care co-ordination requires 'simultaneous innovation' at the organisational/management level in addition to new approaches to care at the clinical/service level. As other studies have shown, without the full alignment of political, regulatory, organisational and professional support to the goals of integrated care, too much reliance is placed on local leaders to make change happen (Goodwin *et al* forthcoming). Ultimately, the long-term future of care co-ordination programmes requires care systems to directly value their contribution in meeting the growing demands of people with long-term and complex chronic conditions.

Appendix A: Methodology

Site selection

The five case studies were selected following a competitive call by The King's Fund across the United Kingdom for care co-ordination programmes to be included in the research. An expert multidisciplinary panel drawn from both the United States and the United Kingdom supported The King's Fund in selecting the sites for inclusion in a review process using objective criteria.

Literature review

The research team carried out a non-systematic literature review to establish the *a priori* criteria for effective care co-ordination with the aim of comparing these criteria with findings from each case study site.

Fieldwork

In-depth case study fieldwork was carried out between October 2012 and May 2013. The research team, consisting of two researchers and a senior research fellow, visited all five case study sites to interview key internal and external stakeholders from multiple professional backgrounds. Semi-structured face-to-face interviews were undertaken, with follow-up by telephone where appropriate. Interviews were recorded, transcribed and analysed using a common coding framework and NVivo software. At each site, the research team also observed at least one team meeting using a template to record team behaviour, topics discussed and actions recorded. Furthermore, the research team carried out content analysis of documents from each site and undertook secondary data analysis to verify each programme's reported outcomes. The table below provides details of the process.

Case study	Date of field visit	Additional interviews (telephone)	Number of interviews	Location
Midhurst Macmillan	8 Oct 2012– 10 Nov 2012	19 Nov 2012– 14 Feb 2013	20	Pulborough, Midhurst
Oxleas	2 Nov 2012; 19 Nov 2012; 26–29 Nov 2012		14	Bexleyheath, Greenwich
Sandwell Esteem Team	14–17 Jan 2013		12	Sandwell, West Bromwich
South Devon and Torbay	11–13 Mar 2013	23 Apr 2013	15	Newton Abbot, Torbay, Ashburton
Pembrokeshire	13–17 May 2013		18	Haverfordwest, Milford Haven, Pembroke Dock

Development days

In addition to the fieldwork, six development days were held, bringing together representatives from each case study programme to discuss common issues and explore how to resolve these. One development day was held at each case study site, with an additional day held at The King's Fund in London.

For more information on the methods used in this research, visit the project website at:
www.kingsfund.org.uk/projects/co-ordinated-care-people-complex-chronic-conditions

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