

Chapter 1

Managing Chronic Conditions: The Policy Context

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Introduction

The rising incidence and prevalence of chronic conditions presents a serious challenge to the effectiveness and sustainability of current and future health-care services. A major issue is the increasing number of people with multiple chronic conditions and health services that continue to be organised around specific diseases. It is evident that chronic kidney disease (CKD) encompasses a spectrum of health states, and that these can be negatively affected by other chronic conditions and age-related problems such as memory impairment and mobility issues. Similarly, socioeconomic factors such as deprivation also adversely influence health outcomes. In effectively meeting the diverse needs of people with chronic conditions, a population management approach is required whereby the focus of care is based on the level of need and extends beyond traditional disease-specific approaches. Successive health policies reflect this shift with initiatives such as 'Our health, our care, our say' (Department of Health 2006) and the long-term conditions National Service Framework (Department of Health 2005) aimed at services being delivered through a 'whole systems approach'. Continuity of care is required across traditional organisational boundaries through more effective collaboration of professionals. Key to this approach is engaging and supporting the patient in self-management. This chapter provides an overview of the changing context of healthcare services, including the innovative work of NHS Kidney Care in working across healthcare sectors and the current policy work which supports a more integrated and collaborative approach in supporting people with chronic kidney disease.

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Chronic kidney disease in context

The effective management of chronic or long-term conditions poses a significant challenge for healthcare systems across the world. In England, around 15 million people have a long-term condition. While the number of people in England is likely to remain relatively steady, the number of people with multiple chronic conditions is expected to rise by a third over the next 10 years. People with long-term conditions account for 29% of the population in England, but are the most frequent users of healthcare services, accounting for 50% of all general practice appointments and 70% of all inpatient bed days. It is estimated that the treatment and care of those with long-term conditions accounts for 70% of the primary and acute care budget in England. This means around one-third of the population accounts for over two-thirds of the spend (Department of Health 2011). More significant than the impact on resources is the effect that long-term conditions have on quality of life. Each year around 170 000 people die prematurely in England, with the main causes being cancers and circulatory diseases. The proportion of people with a limiting long-term condition in work is a third lower than among those without (Department of Health 2011).

Healthcare services continue to be organised around specific conditions. Even for people with a single chronic condition, care is typically provided across a number of different health professionals and organisations. The resultant discontinuity and fragmentation of care can add to an already high disease burden (Nolte & McKee 2008) at the same time as increasing care costs through the duplication of interventions, omissions in treatment and miscommunication. Patient safety is also threatened (Boerma 2006). Whilst improvement initiatives have typically focused on optimising the clinical aspects of chronic care, this alone has not been as effective as wider initiatives that have included service redesign (Coleman *et al.* 2009, Curry & Ham 2010, Goodwin *et al.* 2012). How and where care is provided has important implications for the effectiveness and sustainability of long-term care, and strong primary care is considered to be central to improving patient outcomes and controlling costs (Roland *et al.* 2007). Patient-centred care, self-management support, improved continuity and coordination have all been identified as key contributors of quality in chronic care but can only be delivered through patients, professionals and organisations working more collaboratively together (Wagner 1996, Greaves & Campbell 2007).

Chronic kidney disease (CKD) describes abnormal kidney function and/or structure. It is common, frequently unrecognised, and it often exists together with other conditions (for example, cardiovascular disease and diabetes). The risk of developing CKD increases with age, and some conditions that coexist with CKD become more severe as kidney dysfunction advances. CKD covers a spectrum of health states including an asymptomatic period which is potentially detectable. Tests for CKD are both simple and widely available, and there is evidence that treatment can prevent or delay progression, reduce or prevent

the development of complications and reduce the risk of cardiovascular disease. In cases where progression cannot be prevented, kidney function may deteriorate to stage 5, requiring life-saving dialysis, a kidney transplant or conservative management.

Estimates suggest that there about 4.5 million people in England with CKD. Since 2006, the prevalence of CKD has been reported annually in general practice and has seen a steady rise from 3% to 4.3% in 2009/10. However, compared with an estimated prevalence of 8.8%, diagnosis and ascertainment nationally is still only around half of the expected prevalence. Overall, there are an estimated 1.95 million people in England with undiagnosed CKD, who are therefore untreated and at risk of faster disease progression.

The policy context

In 2010, the UK government set out its long-term vision for the future of the National Health Service (NHS) and health services in England in the NHS White Paper, *Equity and Excellence: Liberating the NHS*. It committed to put the patient at the heart of services through greater choice and control including:

- greater shared decision making and the principle of ‘no decision about me without me’
- greater choice of treatment and access to information
- a focus on personalised care that reflects individuals’ health and care needs, supports carers and encourages strong joint arrangements and local partnerships

Legislation to support this policy direction has since been enacted in the Health and Social Care Act (2012). The White Paper also committed the NHS to focus on outcomes and the quality standards that deliver them. The government’s objectives are to reduce mortality and morbidity, increase safety, and improve patient experience and outcomes for all. To this end, quality standards, developed by the National Institute for Health and Clinical Excellence (NICE), will inform the commissioning of all NHS care.

This approach builds upon and develops further the improvements achieved by the implementation of the National Service Frameworks (NSFs). The NSFs set clear quality requirements for care, based on the best evidence of what treatments and services work most effectively, seeking to ensure an equity of services irrespective of where they are delivered. The NSF for renal services (Department of Health 2004-05) placed a strong emphasis on identifying the condition early in primary care settings, slowing down its progress and minimising its impact on people’s lives. It led to significant improvements in the way kidney disease is managed. The NICE quality standards take this further and are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence

Table 1.1 NHS Quality and Outcomes Framework: five domains, three dimensions.

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	Effectiveness
Domain 3	Helping people to recover from episodes of ill health or following injury	
Domain 4	Ensuring people have a positive experience of care	Experience
Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm	Safety

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such as NICE guidance and other accredited sources, they are developed independently by NICE in collaboration with the NHS, social care professionals, their partners and service users. The quality standards are organised around five national outcome goals or domains, covering the breadth of NHS activity (Table 1.1), and they address the three dimensions of quality: clinical effectiveness, patient safety and patient experience. They enable:

- health and social care professionals to make decisions about care based on the latest evidence and best practice
- patients to understand what service they can expect from their health and social care providers
- NHS trusts to quickly and easily examine the clinical performance of their organisation and assess the standards of care they provide
- commissioners to be confident that the services they are providing are high quality and cost-effective

NICE published its quality standards for chronic kidney disease in 2011 (Table 1.2).

In addition to informing commissioning decisions, quality standards can also be aligned with the NHS funding system to encourage providers to follow best practice. In 2011, a best practice tariff for renal dialysis was introduced, paying significantly more for dialysis sessions that are delivered through definitive access (arteriovenous fistula or graft) than for those that are not. This is known to be better for patients because the faster flow rates result in more effective and efficient dialysis and it is much safer because of the reduced risk of infection. The level of the tariff was set so that providers with 75% (increased yearly by 5% to meet the Renal Association clinical guidelines of 85%) of their patients on definitive access would receive the same level of funding as under the previous system. In addition to rewarding services that do better than this,

Table 1.2 NICE quality standards for chronic kidney disease.

1	People with risk factors for CKD are offered testing, and people with CKD are correctly identified.
2	People with CKD who may benefit from specialist care are referred for specialist assessment in accordance with NICE guidance.
3	People with CKD have a current agreed care plan appropriate to the stage and rate of progression of CKD.
4	People with CKD are assessed for cardiovascular risk.
5	People with higher levels of proteinuria, and people with diabetes and microalbuminuria, are enabled to safely maintain their systolic blood pressure within a target range 120–129 mmHg and their diastolic blood pressure below 80 mmHg.
6	People with CKD are assessed for disease progression.
7	People with CKD who become acutely unwell have their medication reviewed, and receive an assessment of volume status and renal function.
8	People with anaemia of CKD have access to and receive anaemia treatment in accordance with NICE guidance.
9	People with progressive CKD whose eGFR is less than 20 mL/min/1.73 m ² , and/or who are likely to progress to established kidney failure within 12 months, receive unbiased personalised information on established kidney failure and renal replacement therapy options.
10	People with established renal failure have access to psychosocial support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances.
11	People with CKD are supported to receive a pre-emptive kidney transplant before they need dialysis, if they are medically suitable.
12	People with CKD on dialysis are supported to receive a kidney transplant, if they are medically suitable.
13	People with established kidney failure start dialysis with a functioning arteriovenous fistula or peritoneal dialysis catheter in situ.
14	People on long-term dialysis receive the best possible therapy, incorporating regular and frequent application of dialysis and ideally home-based or self-care dialysis.
15	People with CKD receiving haemodialysis or training for home therapies who are eligible for transport have access to an effective and efficient transport service.

National Institute for Health and Clinical Excellence (2011) ‘Chronic Kidney Disease quality standard’. London: NICE. Available from www.nice.org.uk. Reproduced with permission.

the tariff also provided a strong lever for those that were below this level to bring their services in line with best clinical guidance.

A similar tariff for multi-professional outpatient clinics encourages providers to offer patients with complex needs appointments with a multi-professional team (for example, a doctor and a psychologist or social worker)

so that patients are given more choice and control and are able to move to their chosen treatment pathway more quickly. In facilitating support for patient choice and engagement as described in the White Paper, the NHS requires better systems that make it easier for different professionals and services to work more collaboratively together, providing more coordinated and seamless pathways of care. In addition to commissioning more integrated services, commissioners are also able to incentivise providers to deliver services in new ways through the Commissioning for Quality and Innovation (CQUIN) payment framework. This enables commissioners to make a percentage of payments to providers contingent on achieving locally agreed quality improvement goals.

The structure of commissioning is also changing. The Health and Social Care Act paves the way for the introduction of clinical commissioning groups (CCGs), consortia of GP practices that work together to commission services for their local populations. While some elements of kidney care, for example dialysis and transplantation, will be commissioned at a national level, CCGs will be responsible for local services to identify and manage CKD in the community. As member organisations, they will be able to engage with their member GPs on improving standards and sharing good practice; and with their population-based approach they are best placed to look at the most appropriate approaches to the prediction and prevention of CKD and proactive targeted interventions for their patients.

At the time of writing the Department of Health is consulting on a cardiovascular disease outcomes strategy. One of the main aims of this is to better integrate care across a range of associated chronic conditions including CKD, hypertension and diabetes.

The role of primary-care-based integrated teams

While there have been significant improvements in services for people with CKD in recent years, to achieve the ambitions set out in the *Equity and Excellence* White Paper and the best practice guidelines, a greater focus is needed on establishing integrated primary-care-based teams. An important role for these teams will be in determining which groups of patients can be safely managed in primary care and identifying those with more complex needs who are likely to benefit from specialist services. Most stages of CKD can be effectively managed in the community, and this is particularly so in patients whose condition is stable and who require only routine estimated glomerular filtration rate (eGFR) monitoring and lifestyle advice and support such as smoking cessation or weight management.

Appropriately trained nurses can carry out many roles in primary care that have previously been delivered by secondary care specialists. For example, the Intravenous Iron at Home initiative in Cornwall provides CKD patients with iron injections in the community or in their own home, saving them journeys of up to an hour each way for a 10-minute appointment in hospital. The service is

more convenient for patients; it is safer, as there is a lower risk of developing a healthcare-acquired infection; and it saved the NHS an estimated £150 000 in 2010, based on 217 patients with an average of six appointments each year and with a third of them requiring transport or recouping travel costs.

Moving appropriate services to primary care is often cheaper and more patient-centred. Coordinating services can further improve the patient experience by avoiding duplication and omissions of care. People with CKD often have other chronic conditions and will typically receive care from a number of professionals across a number of organisations. Continuity and consistency of care can be improved by multiple providers agreeing roles and responsibilities in the patient pathway and effectively reducing 'duplicate' monitoring appointments and investigations. For example, patients frequently complain about needing to give blood tests for each clinic they attend. It would be more efficient and cost-effective and deliver a better patient experience if one blood test was taken and the results shared across the primary-care-based team. Coordination of care is dependent upon fluid data flows which ensure that patient-related information accompanies the patient to every healthcare encounter.

There are several innovative examples of primary and secondary services working together to offer patients a more joined-up and convenient service while using resources more wisely. For example, an e-mail helpline run by kidney consultants in South Tees is enabling GPs to provide timely, convenient and more efficient care for their patients with kidney disease. GPs can send e-mail questions or queries about specific patients and get a reply within a few hours. This means that patients can receive expert advice and care much more conveniently from their GP and are spared unnecessary hospital visits. The ability to offer more timely care, reduce hospital referrals and discharge patients sooner from outpatient follow-up enables a much more efficient use of NHS resources. The initiative has been well received by GPs and has helped to form strong and positive relationships between hospital consultants and their colleagues in general practice.

There is scope to greatly improve the early identification of patients with CKD. Local health needs assessments have not always been particularly effective at identifying the likely prevalence of the disease, as evidenced by the patchy estimates of the total CKD population. The government's recent introduction of 'Health Checks' in general practice has incentivised the widespread assessment of vascular risk, including CKD. Other initiatives aimed at identifying, monitoring and managing people at risk from chronic conditions are ongoing locally. The Greater Manchester Collaboration for Leadership in Applied Health Research and Care (GM-CLAHRC) is one such programme, and it has recently illustrated the potential benefits for patients with vascular conditions, including CKD, from service providers working collaboratively across traditional boundaries.

Improved assessments will also enable primary-care-based integrated teams to take more of a 'population health' approach which aims to improve the health of a population as a whole rather than narrowly focusing on those

with specific conditions. Population health management (PHM) is distinguished from disease management by including more chronic conditions and diseases, by use of a single point of contact and coordination, and by predictive modelling across multiple clinical conditions. PHM is considered broader than disease management in that it also includes enhanced care management for individuals at the highest level of risk and personal health management for those at lower levels of predicted health risk. Better understanding of local population health needs will enable a reduction in the significant variation in services and outcomes across the country.

From theory to the frontline

There is a clear vision, supported by evidence and clinical guidelines, for improved and more coordinated renal services centred on primary-care-based integrated teams. But how is this being put into practice? Across the NHS there are fantastic examples of good practice and innovative ways of enabling more integrated, seamless and patient-centred care. However more needs to be done to share examples, tools and resources to enable all patients to benefit. At a systems level, there is a wide range of levers and incentives for the commissioning and provision of quality services.

The NICE quality standards set out clear criteria for commissioners of services, and the use of the CQUIN payment framework enables commissioners to reward quality improvements. The NICE quality standards and best practice guidelines such as those from the Renal Association provide a useful guide to areas of focus for improvement. Consistent data collection and sharing between providers and commissioners, through the national Renal Dataset, offers an established set of metrics on which to base assessments of performance. Similarly, the Quality and Outcomes Framework (QOF) provides a set of financial incentives for general practices to carry out certain activities which promote consistency and equity of care. Since 2006, through the QOF, GPs have been paid partly on the basis of how well they identify patients with chronic kidney disease and how well they manage their care.

In secondary care, the use of CQUIN and other financial levers, such as best practice tariffs for haemodialysis and multi-professional clinics, are incentivising best practice and discouraging avoidable variation in care. This will not only lead to improvements in the care provided, but will also have implications for how secondary care services work with primary care, driving improvements across the patients' pathways. For example, providers who are referred patients who require acute dialysis will not be able to offer this through arteriovenous fistula or graft as these can take up to six months to establish. This means that they will be unable to meet the requirements of the best practice tariff, creating a strong incentive to work closely with primary care colleagues to ensure that appropriate referrals are made in a timely manner.

Care or management plans

Early detection is essential in establishing a proactive plan of care, the aim of which is to reduce the impact of CKD on a patient's life and to minimise the risks of the patient's condition suddenly deteriorating into a crisis. This is costly both for the patient and for the health service. All people identified with CKD should be referred to an integrated vascular risk clinic and offered appropriate investigations, including renal ultrasound and immunological tests, to come to a timely diagnosis of the cause of CKD, with referrals to a nephrologist where indicated by the clinical guidelines. Care plans should be developed in partnership between the patient and the integrated team. Self-management should be encouraged and facilitated. Named providers involved in the patient's care should be listed, along with their responsibilities, and these may include nephrologists, dietitians, physiotherapists, nurse specialists, psychologists and social workers. Care planning requires the patient's participation in decision making about his or her own health and care. The aim is to make decisions informed by the best available evidence and consistent with the patient's views on what is important. This often requires ongoing discussions between healthcare professionals, the patient and the patient's family. Evidence shows that involvement in care planning improves patients' ability to self-care, improves concordance with treatment plans and improves their overall health outcomes. For patients referred to secondary care, an increased use of multi-professional clinics will encourage this to happen from the outset, and the care plan will be shared with the patient's GP and community team so that care can be continuous across different providers.

CKD encompasses a number of health states, and care plans are typically individualised to reflect this. They include information on the extent of monitoring and support patients managed in primary care will require, including triggers for when reference to the specialist team is indicated. Regular monitoring and assessment of patients with CKD in primary care reduces the risk of patients 'late presenting', which often prevents a necessary preparation process in which patients have the opportunity to discuss their treatment options over time. The care plan will also set out what other support the patient needs, for example in terms of psychological support or social care. Clinicians and patients report that care planning can also enhance clinic appointments, as less time is needed to explain test results or treatment plans. Within nephrology, partners and/or families are often involved in shaping the treatment plan as patients can become quite dependent upon them for help and support. In providing services for people with CKD it is important to include the needs of any carers involved with the patient as they can often be the sole reason that the patient can be managed at home. This is particularly true for patients on dialysis who need support with travel or with home haemodialysis, which has to be a partnership between the patient and the carer. From the carer's perspective, satisfactory involvement in care planning and decision making requires a strong sense of inclusion in the process. Additionally, carers need to

feel that there is someone they can contact when they need to and that the service is responsive to their needs. Key to the achievement of a patient-centred service is the provision of better information for patients about their condition and its management. The care plan will allow patients to be offered information from a variety of sources in formats to suit their preferred learning styles. This will also include greater access to peer support networks, including peer support for carers.

Conclusion

The needs of people with chronic conditions are complex and varied, and change over time. In meeting these needs, services have traditionally been disease-specific, increasingly specialised and fragmented - factors that perpetuate service inefficiencies, rising costs and patient dissatisfaction. Recent health policy is aimed at addressing these issues by ensuring that services focus more proactively on population health and the wider determinants of health and illness. More emphasis is placed on patients being engaged in their care management, and services working more collaboratively, particularly in primary care. Central to the success of this approach is an individualised plan of care that proactively circumscribes interventions and ensures that professional and patient responsibilities are identified and information appropriately accompanies the patient.

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