Engaging primary care in CKD initiatives: the UK experience

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Abstract
Over the last decade, since the introduction of an international classification of chronic kidney disease (CKD) and the development of simple tools to detect people with CKD, primary care has had to adapt to a new paradigm of disease. Significantly, improved identification of CKD, and increased awareness and understanding of the potential associated adverse outcomes, has in turn required the development, implementation and integration of new policies, models and pathways of care. The UK health care system, including primary care, is uniquely positioned to respond to new initiatives. Despite early reservations, CKD has gone from an unheard of condition in primary care prior to 2006 to one where people with this condition are recorded in disease registers and increasingly managed in accordance with evidence-based guidance. National and local initiatives implemented together have contributed to the improved understanding and management of CKD in primary care in the UK and are showing signs of having made significant health gains in CKD.

Keywords: clinical decision support systems; clinical practice guidelines; estimated GFR (eGFR) reporting; models of CKD care pay-for-performance

Introduction
The Royal College of General Practitioners (RCGP) defines primary care as the first level of contact with people taking action to improve health in the community. Primary care is responsible for the majority of patient contact within the UK National Health Service (NHS), and specialist care consultations, other than in an emergency, can usually only be obtained after a referral from primary care. Primary care in the UK is provided by around 36 000 primary care physicians, known in the UK as general practitioners (GPs) working in 8230 practices with an average list size of 8700 registered patients. GPs, together with roughly 22 000 practice nurses and 5000 care assistants, carry out over 300 million patient consultations a year. Around 82% of the UK population are seen in primary care each year; the average citizen visits their practice 5.4 times per year and roughly 97% of the population are seen within a 5-year period [1]. Two-thirds of consultations are with GPs and 82% of consultations are conducted in practice premises, the remainder being telephone consults, home visits or the very occasional email consultation. Primary care is therefore well positioned to play a prominent role in implementing generic government policy relating to access, choice and self-management when professionally endorsed. This was the process with chronic kidney disease (CKD) where within a national policy context, important guidance was provided by the RCGP and Renal Association (RA).

The introduction of the five-stage classification of CKD, the adoption of estimated glomerular filtration rate (eGFR) reporting from serum creatinine and the recommendations for regular measurements of serum creatinine in high-risk groups have together fundamentally changed the approach to CKD throughout the world [2, 3]. This article will describe national and then local initiatives that have improved identification and management of people with CKD in the UK. We will consider and discuss the impact of these initiatives on specialist services and on enabling primary care to provide quality routine care.

National policy
A fundamental principle of the UK NHS is that services are provided free at the point of care to the entire population and without prejudice. The UK is, in essence, a closed management health care system and as such should be able to provide integrated care. In reality, there are professional, organizational and institutional barriers to coordination and delivery of care in the NHS, some of which can be transcended through implementation of key national policies. Those central to CKD are the Renal National Service Framework (NSF), which was accompanied by an information strategy and included a requirement for eGFR reporting by clinical chemistry laboratories;
national guidance for CKD management; a national programme for information technology (NPfIT) later renamed Connecting for Health (CfH); the high level of computerization of UK primary care and a pay-for-performance (P4P) scheme using routine data to monitor the primary care management of chronic disease, the so-called Quality and Outcomes Framework [4].

The Renal NSF

NSFs provide explicit quality standards for improving care. The Renal NSF followed those in Coronary Heart Disease and Diabetes and the second part, published in 2005, contained two key quality requirements: prevention and early detection of CKD and minimizing the progression and consequences of CKD [5].

eGFR reporting by clinical laboratories

Automated eGFR reporting was introduced nationally from April 2006 using the four-variable isotope dilution mass spectrometry (ID-MS) traceable version of the Modification of Diet in Renal Disease Study equation [6]. The National External Quality Assessment Scheme [7] provides correction factors to generate a creatinine value aligned to the ID-MS reference method from the different creatinine assays employed by laboratories to enable standardized eGFR reporting.

National guidance on identification, management and referral of patients with CKD

To support the NSF, UK CKD guidelines were published by the Joint Specialty Committee of the Royal College of Physicians of London and the RA in conjunction with a number of stakeholder specialist societies and the Department of Health in 2005 [8–10]. This was then superseded by a clinical guideline for the early identification and management of adults with CKD in primary care and secondary care, commissioned from the National Institute of Health and Clinical Excellence (NICE) by the Department of Health [11]. The guideline defined the major components of NHS care provision for CKD and was based on a systematic evaluation of all published clinical and health economics evidence alongside expert consensus, taking account of patient choice and informed decision making. NICE incorporated the five-stage classification of CKD but subdivided Stage 3 CKD into 3A (GFR 45–59 mL/min/1.73 m²) and 3B (GFR 30–44 mL/min/1.73 m²), now adopted internationally. NICE also incorporated the suffix ‘p’ in all stages to denote significant proteinuria (defined as an albumin:creatinine ratio (ACR) of ≥30 mg/mmol or protein:creatinine ratio (PCR) ≥50 mg/mmol).

Another key difference from previously published guidance was the recommendation of blood pressure (BP) ranges, with lower as well as higher limits, in the management of CKD, recommending a systolic BP range of 120–140 mmHg in those with CKD and 120–130 mmHg in those with CKD and diabetes and/or an ACR ≥30 mg/mmol.

NICE have built on the CKD guideline, together with other NHS evidence-accredited sources such as RA clinical practice guidelines [12], to develop quality standards [13], clinical pathways and a commissioning outcomes framework for CKD. Nine of the 15 quality standards (Table 1) are directly relevant to primary care and the primary care–secondary care interface, covering identification of CKD, specialist referral, planning care, cardiovascular risk, BP control, disease progression and acute illness.

National programme for information technology

Launched in 2002, the purpose of NPfIT was to create electronic patient records for every citizen. The project in its original form foundered because it focussed on administrative and technological rather than clinical goals [14]. A key benefit for CKD management has been the roll-out of pathology messaging that links pathology laboratories to practice systems [15].

Table 1. NICE Quality Standards for CKD

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 BP within a target range 120–129 mmHg and their diastolic BP 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 <20 mL/min/1.73 m², and/or who are likely to progress to established kidney failure within 12 months, receive unbiased personalized information on established kidney failure and RRT 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.
Primary care information technology

Primary care computerization in the UK is among the most advanced general practice computing in the world and preceded the development of NPfIT [16, 17]. Six factors contribute to the high quality of general practice computer data:

- An accurate denominator: everyone using the NHS has a unique ID—the NHS number.
- Patients only fully register with one primary care practice. The combination of a unique ID and single practice registration allows accurate estimates of the incidence and prevalence of disease to be generated.
- P4P has led to an improvement in data quality and data recording.
- Computerized links to pathology laboratories mean that pathology data are complete and all automatically posted into primary care computer records. All 169 clinical chemistry laboratories in UK have been electronically linked with all practices since 2007 [15].
- Prescribing records are largely complete, making it possible to identify exactly what drugs are prescribed to people with CKD.
- Routine data are readily extractable for quality improvement and research, something which has proved critically important for the identification of people with CKD [18] and in facilitating nearly all of the local research and quality improvement initiatives described later [19].

Pay-for-performance (P4P) in primary care: the quality and outcomes framework

P4P was introduced on 1 April 2004 for all primary care practices in the UK. Although voluntary, nearly all practices participate and individual practice achievements are published online each year. P4P has four main domains. Each domain consists of a set of measures of achievement, known as indicators, against which practices score points according to their level of achievement. Achievements are measured against over 100 indicators, and practices score points up to a maximum of 1000 points. In England, each point in 2010/2011 was worth £130.51. Achievement is measured using routine clinical data. The average number of total P4P points per practice in each of the 151 NHS localities in England ranged from 891.9 to 981.8 points (89.5–98.2%) of points available in 2010/2011 [20], representing an additional annual income of between £116 415 and £128 160 per practice. The indicators pertinent to CKD are all in the clinical domain and together are worth 38 points. CKD indicators were introduced in April 2006, requiring primary care to produce a register of adults with Stages 3–5 CKD, to measure and record BP annually and to record the percentage of people with CKD, hypertension and proteinuria on treatment with angiotensin-modulating drugs.

The renal indicators have been modified and updated in successive years and from April 2009 include the percentage of patients on the CKD register whose notes record urine ACR or PCR within the previous 15 months (Table 2). In the report for 2010/11, 8245 general practices in England are included in the published results, covering almost 100% of registered patients [20]. Although the CKD indicators are clearly important, there are a number of other areas where high underlying achievement should benefit people with CKD including diabetes (100 points), hypertension (81 points), coronary heart disease (87 points), smoking (60 points), heart failure (29 points), stroke and transient ischaemic attack (24 points), cardiovascular disease primary prevention (13 points) and obesity (8 points). In 2010/2011, achievement overall in all of these areas was at least 93.7%.

Table 2. Quality and outcomes framework CKD indicators, points available and practice underlying achievement 2008–2011*

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<tr>
<td>CKD 1: the practice can produce a register of patients aged ≥18 years old with CKD (US National Kidney Foundation: Stages 3–5 CKD). (R)</td>
<td>6</td>
<td>National prevalence 4.1%</td>
<td>National prevalence 4.3%</td>
<td>National prevalence 4.3%</td>
</tr>
<tr>
<td>CKD 2: the percentage of patients on the CKD register whose notes have a record of BP in the previous 15 months. (P)</td>
<td>6</td>
<td>97.5</td>
<td>97.6</td>
<td>97.5</td>
</tr>
<tr>
<td>CKD 3: the percentage of patients on the CKD register in whom the last BP reading, measured in the previous 15 months, is 140/85 or less. (IO)</td>
<td>11</td>
<td>73.3</td>
<td>73.9</td>
<td>74.2</td>
</tr>
<tr>
<td>CKD 5: the percentage of patients on the CKD register with hypertension and proteinuria who are treated with an angiotensin-converting enzyme inhibitor or angiotensin-receptor blocker (unless a contraindication or side effects are recorded). (P-T-O)</td>
<td>9b</td>
<td>87.3</td>
<td>91.8</td>
<td>90.5</td>
</tr>
<tr>
<td>CKD 6: the percentage of patients on the CKD register whose notes have a record of a urine ACR (or PCR) test in the previous 15 months. (P)</td>
<td>6c</td>
<td>–</td>
<td>77.7</td>
<td>82.2</td>
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*R, register; P, process; IO, intermediate outcome; P-T-O, process linked to outcome.

*bIncreased from four points to nine points in 2009.

cIntroduced in 2009.
Local initiatives in CKD management

Late referral of patients with advanced CKD has been a concern for the last three decades [21]. Publication of prevalence data for CKD from the United States National Health and Nutrition Examination Survey [22] prompted a UK study which showed that significant numbers of people with moderately severe CKD were unknown to their local specialist renal unit [23]. At the same time, it was clear that many patients with early non-proteinuric CKD would be unlikely to gain added value from specialist referral, and that referral of all patients with CKD would overwhelm specialist services. This realization drove the development of the UK CKD guidelines, which in turn have prompted related streams of work to both develop local initiatives for the management of CKD across the health economy and to identify those people with CKD who do not require specialist management.

Local initiatives have included shared care schemes [24, 25], use of disease management programmes [26], implementation of renal patient pathways [27, 28] and information technology-based solutions such as database review to identify high-risk patients [29], introduction of clinical decision support [30] and use of electronic consultation through electronic sharing of health care records between primary and secondary care [31]. These local initiatives have reduced referral rates to specialist care, improved the quality and appropriateness of referrals from primary care, led to both improved management of CKD in primary care and increased confidence in primary care management and possibly, contributed to improved health care outcomes and reduced costs (Table 3).

What has been the impact of national and local CKD initiatives?

The various national and local initiatives in CKD in the UK represent a model of care that transcends primary and secondary care barriers and improves patient outcomes (Figure 1). The goals of such a model are to:

- Provide specific therapy based on diagnosis.
- Slow CKD progression where possible.
- Evaluate and manage comorbid conditions.
- Prevent and manage associated cardiovascular disease.
- Identify, prevent and manage CKD-specific complications (e.g. malnutrition, anaemia, bone disease, acidosis).

Table 3. Local initiatives in CKD management in the UK

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<th>Study</th>
<th>Interventions</th>
<th>Outcomes</th>
<th>Conclusion</th>
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<tr>
<td>949 New referrals with Stages 3–5 CKD (Jones et al. 2006 &amp; 2007) [24, 25]</td>
<td>Management in a shared care scheme with primary care versus a specialist renal clinic</td>
<td>Shared care scheme had a lower risk for death or RRT compared to specialist care, HR 0.64, 95% CI 0.38–0.89 (P = 0.003) adjusted for age, gender, GFR, diabetic nephropathy and vascular disease</td>
<td>30% of patients with Stages 3–5 CKD could safely be managed by shared care</td>
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<td>483 Patients with CKD Stages 4 and 5 identified by an algorithmic approach based on CKD management guidelines (Richards et al. 2008) [26]</td>
<td>Introduction of a primary care-based disease management programme influencing patient education, diet and medicines management</td>
<td>Improvements from baseline at 9 months follow-up in cholesterol (4.2 versus 4.6 mmol/L, P &lt; 0.01), systolic BP (130 versus 139 mmHg, P &lt; 0.05), diastolic BP (71 versus 76 mmHg, P &lt; 0.01) and GFR decline (0.32 versus 3.69 mL/min/1.73 m²/year, P &lt; 0.001)</td>
<td>Introduction of the disease management programme was an effective method of identifying and managing patients with CKD</td>
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<td>CKD referrals to, and subsequent discharge from, a single NHS Trust covering a population of 560 000 (Phillips et al. 2009 [27] and Meran et al. 2011 [28])</td>
<td>Introduction of an Internet-based information resource for primary care management and referral of CKD</td>
<td>Reduction in referral rate, improved appropriateness and quality of referrals, more patients discharged back to primary care per specialist clinic (4.6 to 8.4%)</td>
<td>Use of patient pathways for management and referral of CKD patients improves quality of referral, adequacy of information and promotes safe discharge back to primary care</td>
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<td>Systematic disease management of patients with diabetes and kidney disease from a diverse population of 800 000 (Rayner et al. 2011) [29]</td>
<td>Identification of patients with low or deteriorating eGFR by weekly database review, use of specialist clinics and self-management of BP</td>
<td>31% reduction in follow-up visits, 30% fall below projected requirements for RRT, increase from 26 to 55% in the proportion of patients starting RRT with either a transplant, haemodialysis via a functioning arteriovenous fistula or peritoneal dialysis</td>
<td>Systematic disease management across a large population significantly improves patient outcomes, increases specialist service productivity and could reduce costs</td>
</tr>
<tr>
<td>Appropriateness and quality of 466 new CKD referrals from 17 primary care practices to a secondary care nephrology service (Stoves et al. 2010) [31]</td>
<td>Introduction of electronic sharing of primary care health records with the nephrology service</td>
<td>Reduction in paper referrals, improvement in quality of referral information, reduction in mean interval between the GP sending a referral and clinic attendance from 55 days for a paper referral to 7 days for an electronic response.</td>
<td>E-consultation promotes effective management of patients with mild-to-moderate CKD in primary care</td>
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*HR, hazard ratio; 95% CI, 95% confidence interval.
Plan and prepare for RRT (e.g. choice of modality, access placement and care, pre-emptive transplantation) and reduce late referral.

Provide psychosocial support, conservative care and palliative care options where required.

Serial P4P reports from the NHS information centre since the introduction of CKD indicators detail the improvement in primary care ascertainment of CKD Stages 3–5 in adults aged ≥18 from 2.4 to 4.3% [20]. Following its inclusion in the P4P, recording of proteinuria in primary care has improved both in people with eGFR <60 mL/min/1.73 m² and also in those with GFR >60 mL/min/1.73 m². Local (unpublished) data from a clinical decision support system covering 354,322 of the population demonstrate that of the 110,313 people with eGFR ≥60 mL/min/1.73 m², proteinuria status is now recorded in over 49%. There is an association between achievement of the Quality and Outcomes Framework (QOF) BP targets and the size of the diabetes disease register and incidence of RRT; however, it is too early to know if there is a causal link [32].

Although the implementation of eGFR reporting and the QOF (P4P) led to a doubling of referral of people with CKD reported by several groups in the UK, where local initiatives have also been introduced in conjunction with primary care, the appropriateness and quality of referral have been improved [28, 29, 31, 33–35]. In one area, the proportion of those with Stage 5 CKD expected to be referred from epidemiological data increased from 48% in the 2 years prior to introduction of eGFR reporting and P4P to 82% in the 2-year period post-introduction [34]. The initial increased referral from primary care has also stimulated research to identify those people with CKD at low risk of adverse outcome who can be easily managed either in primary care or in a shared care scheme [36, 37].

**Confidence in managing CKD in primary care**

A diagnostic analysis prior to the start of the Quality Improvement in Chronic Kidney Disease trial [38] suggested that many GPs and practice team members had little shared understanding of CKD with some reporting they felt CKD to be a biochemical construction or medicalization of a normal ageing process [39]. A subsequent exploration of confidence and competence in managing CKD showed that there was a good understanding of CKD and when to refer, but that confidence remained patchy. However, higher levels of confidence were associated with higher quality of care [40].

**Professional leadership at the time of implementation**

Leaders in primary care and renal medicine sought to plug any gaps in knowledge or data provision. Knowledge gaps were filled by the British Medical Association and NHS Employers commissioning a set of ‘frequently asked questions’, now in its third edition [41].

**Potential adverse consequences**

Overall, the evidence that P4P has driven up the quality of primary care in the UK is weak [42–44], but we consider that the inclusion of the CKD indicators has almost certainly driven up awareness and confidence in managing CKD in primary care. More demanding targets (such as those set in CKD), aligning payment to the correct ‘goal gradient’ and a focus on outcome measures may achieve greater benefit [45].

Not all commentators agree that routine reporting of eGFR is beneficial. Some express the opinion that a reduction in GFR with age should be considered normal, and that referral of older patients with non-proteinuric CKD is a form of ‘disease-mongering’, raising unnecessary anxiety amongst people whose overall risk of requiring RRT is low [46]. This has caused considerable controversy [47]. There has been no systematic attempt to measure ‘illness behaviour’ amongst patients newly ‘labelled’ with the diagnosis of CKD, and this is regrettable.

**Conclusion**

New structures have been put in place, primarily in pathology departments, to identify people with CKD, who prior to 2006 would have largely gone unrecognized in primary care. In less than 5 years, primary care, supported by their specialist colleagues and policy changes including P4P has implemented systematic management of a chronic condition. Over 4% of the adult population are now included on CKD disease registers [20], a remarkable achievement but not yet reaching the prevalence expected from the epidemiological study, there is still more to be done [48, 49].

On balance, we believe that evidence is accumulating that the national and local policy initiatives we describe have done considerably more good than harm. The overall incidence of end-stage kidney disease in the UK has stabilized at 109 patients per million per year and remains lower than in many other developed countries; and the late referral rate has fallen from 27% in 2004 to 19% in 2009 [33]. These observations are indirect but powerful...
evidence that the policy and practice changes we have described have improved the outcome for many patients with CKD. The next challenge for the UK is to do the same for acute kidney injury.

Conflict of interest statement. None declared.

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