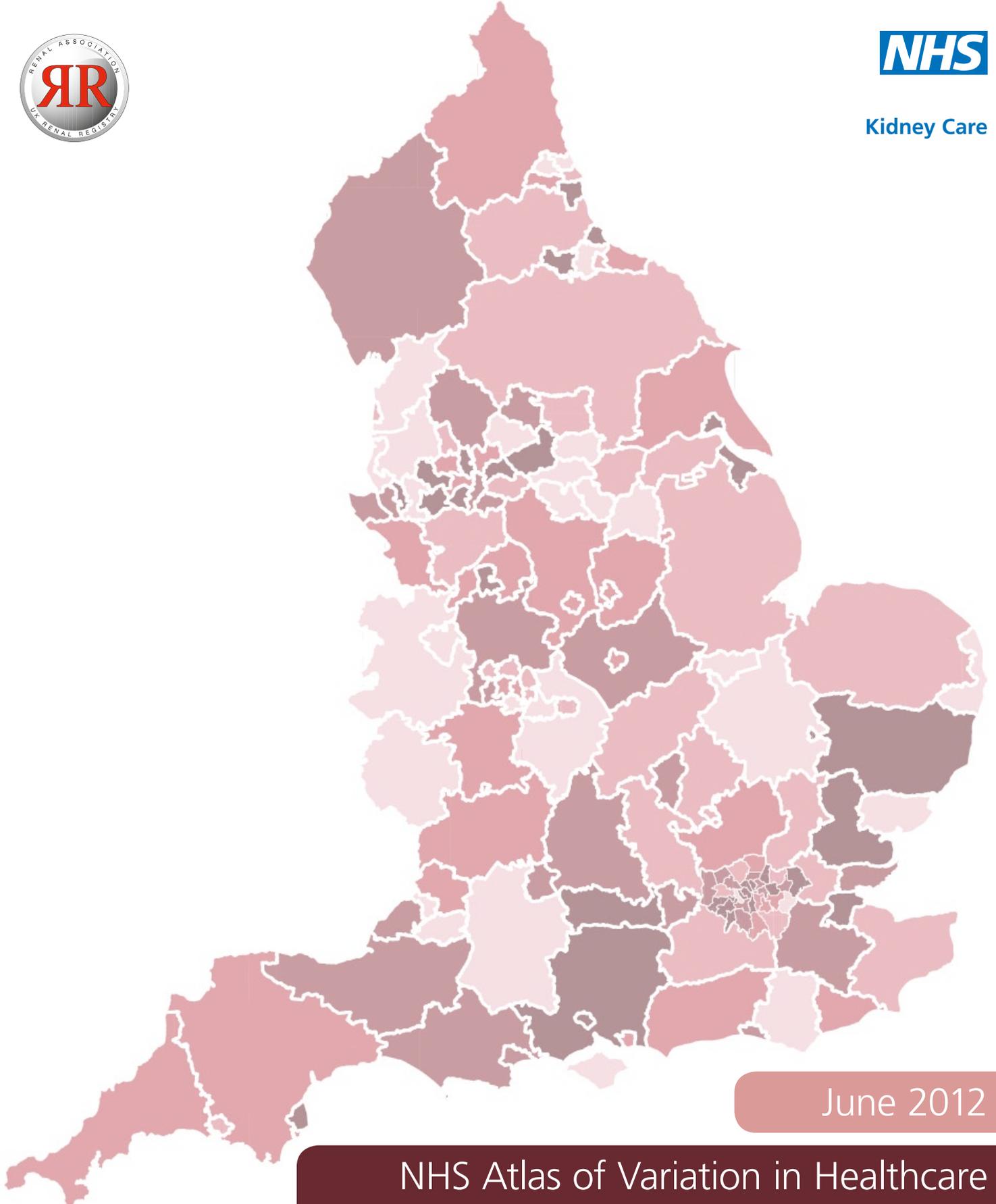




NHS

Kidney Care



June 2012

NHS Atlas of Variation in Healthcare for People with Kidney Disease

Reducing unwarranted variation to
increase value and improve quality

RightCare 

www.rightcare.nhs.uk

June 2012

NHS Atlas of Variation in Healthcare
for People with Kidney Disease

Reducing unwarranted variation to
increase value and improve quality

The Kidney Care Atlas has been prepared in partnership with a wide range of organisations:



Kidney Care

NHS Kidney Care works with healthcare professionals and commissioners to improve every aspect of kidney care for patients. From improved prevention and early diagnosis through to better end of life care, we support healthcare professionals to understand and implement new guidelines, standards and national priorities and we support patients and their carers to make more informed choices and live life to the full.

<http://www.kidneycare.nhs.uk/>



The UK Renal Registry (UKRR) was established by the Renal Association to act as a resource in the development of patient care in renal disease. The Registry acts as a source of comparative data for audit, benchmarking, planning, policy and research. The collection and analysis of sequential biochemical and haematological data is a unique feature of the UKRR. The Registry is open to influence from all interested parties, including clinicians, NHS Trusts, commissioning authorities and patient groups.

<http://www.renalreg.com>



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NHS Information Centre for health and social care (NHS IC) is England's central authoritative source of essential data and statistical information for frontline decision makers in health and social care.

<http://www.ic.nhs.uk>



Healthcare Quality Improvement Partnership (HQIP) was established in April 2008 to promote quality in healthcare, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. It is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices (formerly the Long-term Conditions Alliance). HQIP sees clinical audit as one essential tool in a much broader range of activity to improve quality in healthcare.

<http://www.hqip.org.uk/>



East Midlands Public Health Observatory (EMPHO) is one of nine Public Health Observatories in England, which work together through a single national work programme consisting of national and local elements. We produce information, data and intelligence on people's health and health care for practitioners, policy makers and the wider community. Our expertise lies in turning information and data into meaningful health intelligence to support decision-makers.

<http://www.empho.org.uk>



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Case-studies provided by:



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<http://www.kch.nhs.uk/>



Aintree University Hospitals NHS Foundation Trust has a vision of being "a provider of high-quality, patient-centred healthcare with a first-class local, national and international reputation". Our strategic objectives are to deliver high-quality, safe patient care, to develop staffs' potential, to deliver our targets and obligations, and to develop effective external partnerships. Our values are supported by our behaviours, which will enable our staff to deliver our strategic objectives and our vision.

<http://www.aintreehospitals.nhs.uk/>



Nottingham University Hospitals NHS Trust is now one of the biggest and busiest acute Trusts in England, employing 13,000 staff. We provide services to over 2.5 million residents of Nottingham and its surrounding communities. We also provide specialist services to a further 3–4 million people from neighbouring counties each year. We have achieved a national and international reputation for many of our specialist services, including stroke, renal, neurosciences, cancer services and trauma.

<http://www.nuh.nhs.uk/>

Right Care continues to pay homage to the inspirational publication, *The Dartmouth Atlas of Health Care*, and the vision and commitment of Professor John Wennberg who first charted this territory.

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Foreword

Variations in the care provided to patients do exist. Some variation is warranted by the defining needs of each local population, but some variations are unwarranted. Unwarranted variation can result from three main factors: under-use or inappropriate use of effective care, physician opinion, when patients are inadequately informed and supported during decision-making about preference-sensitive care, and the influence supply exerts on the intensity of care delivered either due to failure to provide a particular service locally or, more usually, because of the assumption that more care is better care. In the *NHS Atlas of Variation in Healthcare for People with Kidney Disease*, examples of unwarranted variation in all three categories are presented.

It is increasingly being recognised that illness, the level of disease, and illness behaviour, the individual recognition of illness and presentation for care, account for only a small degree of variation in the care delivered.

The fact that populations do differ – the population needs and “right” amount of care in Bradford are different from those in Bournemouth – may be particularly important in kidney care. For conditions such as chronic kidney disease and acute kidney injury, age and ethnicity are key determinates of the incidence and prevalence of disease. Therefore, some variation in kidney care is warranted because populations differ, and “uniform” care would neither be responsive to local factors nor provide the opportunity for innovation to strengthen the science of healthcare delivery. The risk associated with providing uniform care consigns us to the past, and, while accepting that “right” care will vary, it is clear that there is no need for it to vary to the extent shown in the Kidney Care Atlas.

What does the variation shown in the Kidney Care Atlas mean for patients, their carers and their families?

From my point of view, as a kidney doctor for over 25 years, one of the most enduring themes has been encountering missed opportunities to identify kidney disease early, therefore not being able to prevent its complications or enable the planning of future care in partnership with patients. For individual patients, the late identification of kidney disease means delays in diagnosis, failure to manage risk factors, resulting

in premature vascular events (heart attacks, strokes and heart failure) or progressive kidney disease, and starting dialysis in an unplanned way, with attendant increased hospitalisation, morbidity and mortality. For some patients, it means starting dialysis when it would have been better to have received a pre-emptive live-donor kidney transplant and thereby avoided the need for a period of time on dialysis prior to transplantation. For others, it means receiving haemodialysis via an indwelling venous, rather than an arterio-venous, fistula, which can take several months to mature, thereby risking bloodstream and disseminated infection. Such chaotic care is costly – not only in financial terms or in terms of the healthcare professional’s time and focus, but, most importantly, in human terms for patients and their families.

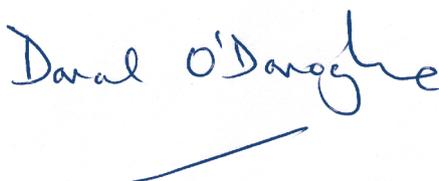
Patients with kidney disease face many difficult decisions. Which modality of renal replacement therapy? Which type of dialysis and where should it be administered – in the home or hospital setting? Whether or not to be transplant listed, particularly if there are relative contra-indications increasing risk? For the frail and those with low functionality unable to manage many of the activities of daily living, whether or not to opt for conservative kidney care (no-dialysis but maximum medical therapy option)? All these are known as preference-sensitive decisions. Such decisions are best made by patients in partnership with, and supported by, healthcare professionals using formal decision aids. In this way, people with kidney disease are aware of their individual risks and prognosis, as well as what each option will mean for them. Patients are then able to consider these biomedical and logistic factors in the light of their personal values, attitudes and beliefs to reach shared decisions for treatment and advanced care planning. Small area variations tell a story about local care that will be of as much interest to patients and their advocates as well as to service providers and commissioners of care.

Not everything we measure in healthcare is important, and not everything that is important is measured. The indicators in the Kidney Care Atlas have been chosen by the expert team assembled by NHS Kidney Care and Right Care because they are important reflections of the

quality and value of care. Although we cannot provide the “right” answers – there is no magic percentage – the Kidney Care Atlas does pose the right questions for local networks to address in partnership with patients.

Exploring the questions the Kidney Care Atlas raises should prompt improvements in the local organisation of care delivery, building on the best examples that

currently exist, promote a shift to establishing shared decision-making systems between patients and healthcare professionals as the norm for preference-sensitive care, such as choice of modality of renal replacement therapy or whether to opt for conservative care, and strengthen the science of healthcare delivery to foster innovation and put effective care delivery on a solid scientific foundation.

A handwritten signature in blue ink that reads "Donal O'Donoghue". The signature is written in a cursive style and is positioned above a single horizontal line.

*Dr Donal O'Donoghue FRCP
National Clinical Director for Kidney Care
May 2012*

Reducing unwarranted variation: right care for people with kidney disease

One of the founding principles of the NHS is to provide equity of care to the whole population. The aims in publishing the *NHS Atlas of Variation in Healthcare for People with Kidney Disease* are twofold.

1. To identify variation not only in the quality of kidney care but also in the availability of certain treatments across England
2. To suggest reasons for variation and the ways in which that variation could be addressed to increase value

However, when identifying variation, it is important to bear in mind that the services commissioned in a locality need to reflect and respond to the needs of the local population, and that those services need to be effective and make a difference to the lives of local people. Therefore, some geographical variation is to be expected.

Despite the importance of meeting local needs, it has become increasingly apparent that some variation is unwarranted. Professor John Wennberg defined unwarranted variation as:

“Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences.”¹

In some instances, unwarranted variation means that:

- people may not have access to certain services;
- the quality of care people receive may not be of the same standard as that provided elsewhere in the country.

The NHS has a responsibility to all patients in its care, and the existence of unwarranted variation can cause tensions in the relationships between patients, healthcare providers, commissioners and policy-makers.

Understanding why variation occurs in the NHS is critical to our ability to deliver safe, efficient, effective and equitable healthcare to all.

From tonsils to kidneys

The initial appreciation of unwarranted variation in healthcare can be traced back to the first decades of the twentieth century. The physician J Allison Glover, while working for the Ministry of Health, had become aware of what he described as a “great vogue” for performing tonsillectomies in schoolchildren. In a now seminal paper based on an analysis of school medical records, Glover documented a doubling in the number of tonsillectomies performed across England and Wales between 1919 and 1937.² He also described an almost fourfold variation in the incidence of tonsillectomy among regions. Glover commented that for the number of tonsillectomies performed there was:

“no correlation between the rate of incidence and any impersonal factor, such as overcrowding, poverty, bad housing, or climate.”

He suggested that the utilisation of the procedure was due to “variations of medical opinion on the indications for operation”. “Living experiments” (a term used by Wennberg) appeared to confirm Glover’s suggestion. He recorded tonsillectomy rates in one school in Hornsey, north London, both before and after a change in the school doctor. The exiting doctor had been an advocate of tonsillectomy whereas the new appointee was not, and subsequently rates fell. A post-operative complication rate of 85 child deaths per year crystallised Glover’s doubts over the value of the procedure, and he echoed the School Epidemic Board’s belief that:

“there is a tendency for the operation to be performed as a routine prophylactic ritual for no particular reason and with no particular result.”

1 Wennberg JE (2010) *Tracking Medicine. A Researcher’s Quest to Understand Healthcare*. Oxford University Press. <http://www.dartmouthatlas.org/>

2 Allison Glover J (1938) The Incidence of Tonsillectomy in School Children. *Proceedings of the Royal Society of Medicine* May 1938; 1219-1236.

Thirty years later, tonsillectomy rates were investigated in the United States of America; much the same degree of variation was identified. It appeared that the procedure was performed according to the beliefs of the operator with no clear basis on which to guide practice.

This phenomenon is not restricted to tonsillectomies or to other surgical procedures. Wennberg publicised and popularised the study of unwarranted variation in *The Dartmouth Atlas of Health Care*.³ Investigating several different care programmes provided by the Medicare system in the USA, he uncovered further peculiarities in the delivery of healthcare.

The findings in *The Dartmouth Atlas of Healthcare* are sobering:

- increased spending and greater use of health services does not necessarily result in better outcomes;
- much of medical practice remains empirical.⁴

One of the impacts of *The Dartmouth Atlas of Health Care* has been to promote the study of variation in many other countries, including England. Between 1995 and 2001, it was found that the standardised mortality ratio (SMR) in hospital varied fivefold across NHS Trusts in England,⁵ and there has been press coverage of inconsistencies in access to cancer drugs and fertility treatment. However, despite the research on variation undertaken in academia, it is only in the last two years that the NHS in England has been able to replicate comprehensively the work pioneered at Dartmouth.

The NHS Atlas of Variation in Healthcare was first published in 2010 by Right Care, in which were visualised the geographical differences in 34 healthcare-related indicators across England. The contents of Atlas 1.0 and Atlas 2.0 (published the following year in November 2011) have demonstrated that variations within medical and surgical specialties continue to exist in England;⁶ kidney care is no exception.

Pioneering the study of variation in kidney care in England

To characterise and understand variation, it is necessary to have access to comprehensive data on not only the health services being provided but also the population being served. The kidney community has access to a considerable amount of data about the delivery, quality and value of renal services from a variety of sources.

The UK Renal Registry (UKRR) was established by the Renal Association with support from the Department of Health, the British Association of Paediatric Nephrologists, and the British Transplant Society as a resource for the development of patient care in renal disease.⁷ Publishing its first annual report in 1998, the UKRR has collected data for many years on patients with advanced kidney disease and been able to highlight differences among renal centres in the UK. In addition, data on primary care management of chronic kidney disease (CKD) are becoming increasingly available since goals for treatment success were incorporated into the Quality and Outcomes Framework (QOF),⁸ thereby enabling variation in the community to be assessed.

The Kidney Care Atlas is a landmark in the study of variation in kidney care in England. Data from the UKRR and QOF, as well as other datasets, have been used to illustrate how some aspects of healthcare specific to kidney disease vary. As is the case for any healthcare atlas, visualising data as a map has an immediate impact with the power to communicate the information effectively to commissioners, providers and patients, a power perhaps above and beyond that which could be achieved by publishing large tables of data. It is in the contextualisation of information that the true strength of the Kidney Care Atlas lies.

However, although the indicators reveal to a certain extent the degree of variation in the care of patients with kidney disease in England, the question they cannot address is why such variation exists. Thus, the next challenge is to distinguish between the variation that is warranted and the variation that is unwarranted.

3 Wennberg J et al (1996) *The Dartmouth Atlas of Health Care*. <http://www.dartmouthatlas.org/downloads/atlas/96Atlas.pdf>

4 Wennberg J (2002) Unwarranted variations in healthcare delivery: implications for academic medical centres. *British Medical Journal* 325; 961–4.

5 The NHS Confederation (2004) Variation in Healthcare: Does it matter and can anything be done? <http://www.nhsconfed.org/Publications/Pages/Variationinhealthcare.aspx>

6 Right Care (2010) *The NHS Atlas of Variation in Healthcare 2010* and *The NHS Atlas of Variation in Healthcare 2011*. <http://www.rightcare.nhs.uk/index.php/nhs-atlas/>

7 The UK Renal Registry <http://www.renalreg.com/>

8 The NHS Information Centre Quality and Outcomes Framework <http://www.qof.ic.nhs.uk/>

Understanding unwarranted variation in kidney care

Differentiating between warranted and unwarranted variation is more difficult than it may seem at first sight. For example, one immediate explanation for a higher level of observed CKD in a locality might be that there is a greater proportion of elderly people living in that population. However, it is easy to adjust for such factors as age, and standardisation has been used where possible when constructing the indicators in the Kidney Care Atlas. However, even after standardisation for some factors, geographical differences remain.

To understand the reasons for such variation, Wennberg identified three types of unwarranted variation:

- Effective care;
- Supply-sensitive care;
- Preference-sensitive care.

All three types of unwarranted variation are relevant to aspects of the care of patients with kidney disease.

Effective care

Effective care comprises patient services that confer proven benefits which outweigh the risks associated with those services. Thus, effective care should be provided to all appropriate patients who have a relevant specific medical need. Such interventions or treatments need to be supported by a robust evidence base to guide their use.

As there is a paucity of randomised controlled trials (RCTs) in nephrology when compared with other medical specialties,⁹ there is a paucity of robust evidence on which to base effective care. However, this situation is changing. Although historically patients with CKD were excluded from research studies, more inclusive studies are now being performed, and guidance for best practice has been produced by several organisations, including the Renal Association.¹⁰ For instance, there is a recommendation that all CKD patients with hypertension and proteinuria should be treated with an angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB).¹¹

9 Strippoli G et al (2004) The Number, Quality, and Coverage of Randomized Controlled Trials in Nephrology. *Journal of the American Society of Nephrology* 15: 411–419.

10 The Renal Association – Clinical Practice Guidelines. <http://www.renal.org/clinical/guidelinessection/guidelines.aspx>

11 NICE. Chronic Kidney Disease Guideline (CG73) <http://guidance.nice.org.uk/CG73>

12 Shain M, Roemer MI (1959) Hospital costs relate to the supply of beds. *Modern Hospital* 92(4):71-3.

Effective care relates not only to treatments but also to investigations. The identification of patients with CKD, and their entry on a register, is important because it enables effective treatments, such as ACE inhibitor/ARB therapy, to be directed to these patients. Both of these treatments are measured in the QOF (see Maps 3 and 4, pages 26–29).

Supply-sensitive care

Supply-sensitive care refers to services whose pattern of use is related not to any underlying medical evidence but to the availability of services instead. The existence of investigations, interventions or other treatments appears to result in their utilisation. As the availability of services increases, so does the level of utilisation, irrespective of whether the services are needed. This situation is encapsulated in Roemer's Law (after the American public health researcher¹²), first coined in the 1960s:

"A hospital bed built is a bed filled."

There are several examples of Roemer's Law in kidney care.

1. Access to nephrologists in hospital can lead to increased frequency of outpatient follow-up of patients with stable CKD stage 3. As many of these patients will not progress to end-stage renal disease (ESRD), it could be argued that their care might be more appropriately delivered in the community. There are alternative pathways to look after such patients in primary care, which are being developed (see Case-study 1, page 57). The use of these primary care pathways will enable secondary care to focus on CKD patients who need specialist input.
2. In the UK during the 1980s and early 1990s, there was an under-supply of haemodialysis, and in-centre and satellite haemodialysis capacity increased over time to meet demand. However, it could be postulated that, although much haemodialysis use is warranted, it might divert resources away from the use of other renal replacement therapy (RRT) modalities or non-RRT options. The variation in standardised acceptance ratio (SAR) for RRT, such as dialysis, by primary care trust (PCT) is shown in Map 6 (page 32).

Preference-sensitive care

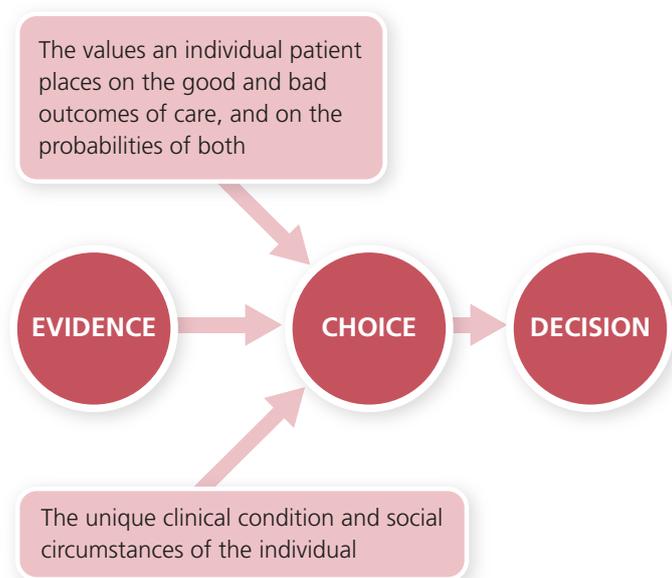
There are many scenarios in medicine where more than one course of action exists, such as:

- to have an investigation;
- to undergo a surgical procedure;
- to take a drug.

If there is a robust evidence base to guide the patient on the best course of action, efforts should be made to follow the evidence to ensure that the most effective care is provided.

Sometimes, no such evidence exists, and many possible options are available. In these situations, the role of the healthcare provider is to educate the patient about the risks and benefits of each option. Ultimately, however, the decision to take a certain course of action must be guided by the values and preferences of each individual patient (see Figure I.1).

FIGURE I.1: INDIVIDUALISING CARE THROUGH SHARED DECISION-MAKING



Such preference-sensitive care can occur only when a patient has had the time to consider each available option and reach an informed decision. Variation in preference-sensitive care is often influenced by medical opinion, as exemplified by Glover's work on tonsillectomy in children at the start of the twentieth century. The phenomenon is observed in many aspects of kidney care.

1. The decision whether to have RRT is complex, emotive and personal. It is not a decision that can be made quickly, and sometimes patients are asked to make one in haste. When compared with a more conservative form of care, starting dialysis may not be the best course of action for very frail and infirm elderly patients. Similarly, it may not be the best course of action for a patient who has a possible kidney donor.
2. The decision whether to have dialysis at home or in hospital is a patient's personal choice, but one that can be influenced by the values and beliefs of dialysis providers. The variation in the proportion of patients receiving dialysis at home by renal centre is shown in Map 10 (page 40).

Defeating unwarranted variation

The identification of variation and then distinguishing between warranted and unwarranted variation are the first steps in a process. The identification of unwarranted variation is redundant unless it provides a platform for implementing change. The task of addressing unwarranted variations in kidney care nationally falls on all the professionals involved in organising and/or delivering care. The influence of patients and patient groups in shaping care can be profound, and their expertise should be utilised not only to help to design and improve healthcare services but also to combat all three types of unwarranted variation (see above).

The under-use of effective care in renal services is generally the result of the organisation of local healthcare systems or, as described by Wennberg and Wennberg, a proliferation of "nonsystems" of care.¹³ To confer benefit on patients irrespective of where they live, effective care needs to be implemented nationally. Embedding good practice, as defined in NICE or Renal Association guidelines, requires raising awareness among, and changing the culture of, the healthcare professionals who are responsible for prescribing ACE inhibitors in CKD or for preparing patients for dialysis.

Financial remuneration – such as incentives in the QOF system in primary care or best practice tariffs in secondary care – can be used to spearhead a widespread uptake of effective care. This strategy has been used to some effect in England: to receive QOF payments, GPs are required to have 80% or more of their CKD-registered patients on ACE inhibitors/ARBs (see Map 3, page 26). As further data become available,

13 Wennberg D, Wennberg J (2003) Addressing Variations: Is There Hope For The Future? *Health Affairs* December 10, 2003 (ePub).

reviewing and adapting such benchmarks can ensure that patients benefit from the best care as guided by the best evidence.

Whereas effective care should transcend geographical divides, preference-sensitive care will, by its nature, vary to a certain degree and presents a greater challenge when addressing unwarranted variation. The driver of variation in preference-sensitive care is the healthcare provider because clinicians prescribe the therapy or give advice on interventions. As culture change can be difficult to achieve, targeting the patient as a catalyst for culture change might have a greater effect overall. In general, patients want to be more involved in their care, and informed patients tend to have better outcomes than those who are less empowered. A patient-driven health service is a key priority for the Government as exemplified by the maxim:

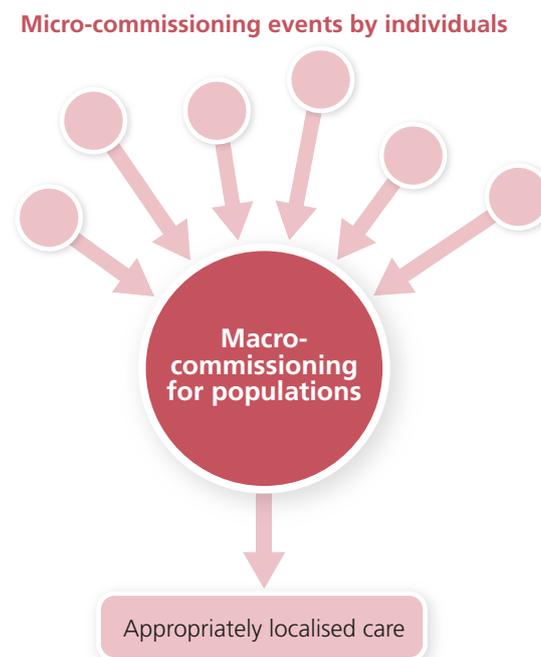
*“No decision about me, without me”.*¹⁴

Self-care support, personalised care-planning and shared decision-making are all tools to assist patients to individualise their care (see Figure I.1).

The use of shared decision-making and sophisticated decision-support tools is highly appropriate for kidney care, especially when patients are faced with making choices about renal replacement therapy. Guidance on how to develop such tools for use in the community, renal centres and renal networks has become more widely available, and NHS Kidney Care is working to embed these concepts nationally through its Shared Decision Making and Care Planning workstreams (for further information, see <http://www.kidneycare.nhs.uk>).

Shared decision-making can generate information to guide the commissioning of services in a way that ensures healthcare is delivered appropriately to minimise unwarranted variation. Every decision by a patient to have a peritoneal dialysis catheter inserted can be viewed as a “micro-commissioning” event, in which the patient has requested that a service be provided for them. If this information were to be captured and fed forward, it could guide larger scale or “macro-commissioning” for the local population. In diabetes, understanding micro-commissioning patterns has led to the provision of appropriately localised care in some areas (see Figure I.2), including funding for some services that otherwise might not have been provided.¹⁵

FIGURE I.2: USING PATTERNS OF MICRO-COMMISSIONING TO GUIDE MACRO-COMMISSIONING AND LOCALISE KIDNEY CARE



Thus, although shared decision-making brings direct benefits to patients, there is the potential to reduce unwarranted variation in preference-sensitive care through informed commissioning. It is because of this multiplicity of benefits that The King’s Fund refers to shared decision-making as “an ethical imperative.”¹⁵

Increasing value, improving quality

In the Kidney Care Atlas, there are 18 indicators, which comprise only a sample of the indicators that could have been selected to show the variation in the value and quality of renal services across England. Identifying, mapping and attempting to address unwarranted variation should not be regarded as independent pursuits, but instead be perceived as intertwined with the quality improvement agenda for renal services. Simply meeting targets for investigation and treatment is not enough. Listening to patients and altering systems of care according to their experiences is intrinsically linked to improving the quality of care. It is through the efforts of individual clinical teams working “on the shop-floor” that change must be implemented, value increased and quality improved so that unwarranted variation can be addressed.

The journey may be demanding, particularly during a time of fiscal constraint. However, in such circumstances,

¹⁴ Department of Health (2010) Liberating the NHS. <http://www.dh.gov.uk/en/Healthcare/LiberatingtheNHS/index.htm>

¹⁵ Coulter A, Collins A (2011) Making Shared Decision-Making a Reality. The King’s Fund. http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html

it is important not to lose sight of the NHS' founding principle to provide equity of care for the whole population. There is a clear need to improve and develop the care provided for patients with kidney disease. As the Kidney Care Atlas reveals, there is considerable scope for improvement:

- › Current trends in the risk factors for CKD suggest a continued increase in the number of people with CKD into the foreseeable future;
- › The option to have dialysis at home is not universal;
- › Some people who might benefit from transplantation do not have the opportunity;
- › The outcome for patients in hospital with acute kidney injury is variable.

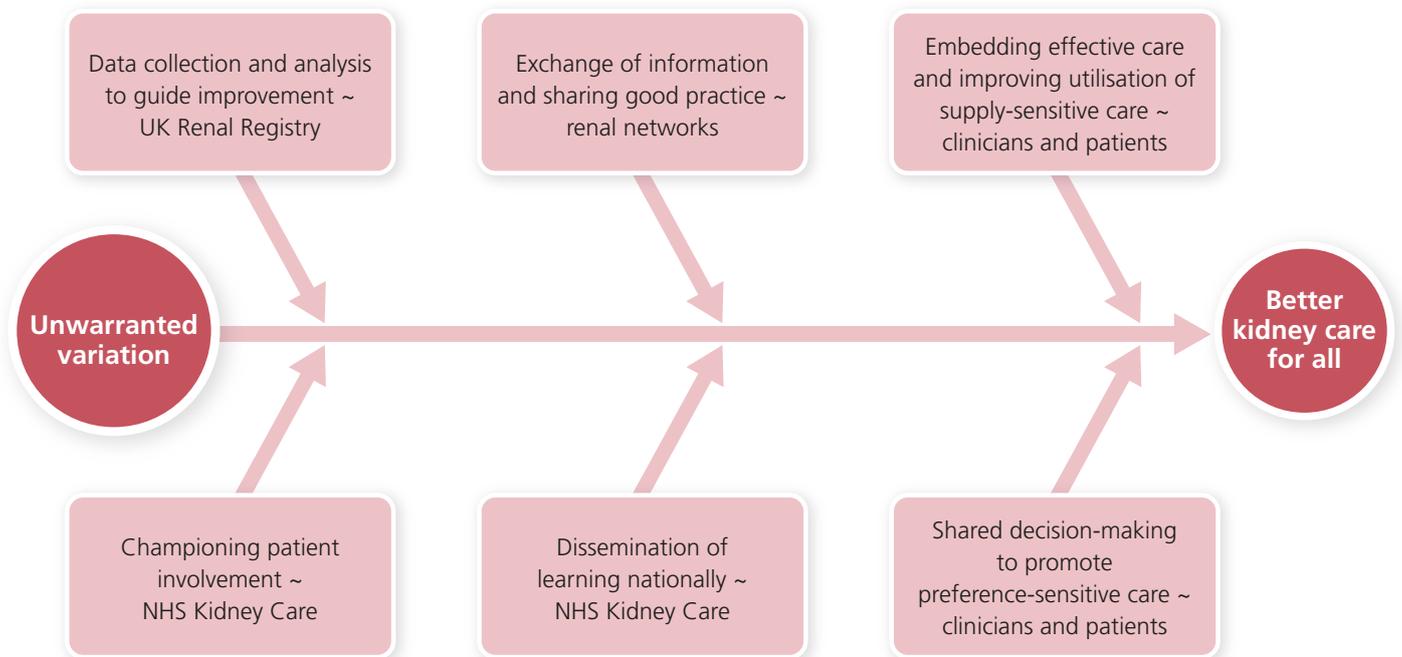
Fortunately, this is not a journey that needs to be made without guidance (see Figure I.3). Under the leadership of the UKRR, more data are being collected to help direct the course of improvement. The focus is being refined towards useful markers of quality

and patient-related outcome measures (PROMs), although research into which markers are appropriate and effective is needed. Renal networks enable the exchange of information and the sharing of good and promising practice in order to reduce disparities locally. Organisations such as NHS Kidney Care can help:

- › to disseminate learning nationally;
- › to reproduce good practice where necessary;
- › to champion patient involvement.

There are many individuals – healthcare professionals and people affected by kidney disease – who have the leadership qualities, vision and passion to work towards embedding effective care throughout the NHS, as well as improving the utilisation of supply-sensitive care and promoting preference-sensitive care. With this drive and the appropriate support, reducing unwarranted variation, increasing value and improving quality should be an achievable goal so that ultimately there is better kidney care for all.

FIGURE I.3: ADDRESSING UNWARRANTED VARIATION IN KIDNEY CARE



Map and chart presentation

Selection of indicators

Experts in nephrology, professionals from general practice, public health observatories and Department of Health policy teams and representatives from patient groups were consulted about the selection and development of the indicators in the Kidney Care Atlas. The indicators chosen cover many aspects of kidney care including prevention and management in primary care, secondary care treatments and patient-reported outcome measures (PROMs). The main reason for selecting each indicator was whether it might reveal potentially unwarranted geographical variation.

Limitations of data quality and availability have precluded the inclusion of some topics that would benefit from variations analysis. Some of the indicators, notably those that are drawn from datasets comprising returns from individual renal centres, vary in the completeness of data; where relevant, this has been highlighted in the commentary.

The contents of the Kidney Care Atlas should be viewed as a stimulus for debate. Many aspects of kidney care covered by the indicators are not as yet supported by findings from a robust research study to explain the differences observed. Hence, the Kidney Care Atlas serves to encourage commissioners and clinicians to investigate health outcomes in local populations.

Order of appearance

Indicators relevant to chronic kidney disease and its management in the community are presented first, followed by indicators featuring renal replacement therapy including transplantation and dialysis access. Acute kidney injury in secondary care comprises the third section of indicators, and finally there are indicators relevant to patient experience.

Data sources

Data for most of the indicators in the Kidney Care Atlas have been extracted by colleagues at the UK Renal Registry, the East Midlands Public Health Observatory (EMPHO), and Solutions for Public Health (SPH) from a variety of sources including:

- › The Quality and Outcome Frameworks online database;
- › Hospital Episode Statistics (HES);
- › UK Renal Registry data;
- › NHS Blood and Transplant (NHSBT) data;
- › National Kidney Care Audits for Vascular Access and Patient Transport.

Classification

Data for each of the indicators are displayed as both a column chart and map to show variation in terms of magnitude and geographical location within England. London is shown as a page inset on all PCT and renal centre maps to keep detail that otherwise might be lost.

The charts and maps for all indicators are colour classified into thematic displays, which group the indicator values into categories and allow the reader to view and compare them on the column chart and map without having to refer to individual values. Data are displayed on the maps as either geographical areas (e.g. PCTs) or renal centres.

A simple method of classification using equal counts of geographical areas or renal centres was used to display all indicators, regardless of distribution of data within indicators. Five equal counts of areas/centres or 'quintiles' were classified for all indicator data where possible. However, as most of the indicators include a total number of areas or centres that are not divisible by five (e.g. 152 PCTs or 52 renal centres), in most cases the classifications do not include exactly the same number of areas or centres. The method used to create the classification was to rank order the areas or centres from highest to lowest values, then divide the ranks into five equal categories. However, in some cases, indicators included tied ranks (i.e. where some area or centre values were exactly the same) and no areas or centres were split into different categories if the rank was equal; this meant that an equal split was not possible in these cases. For the few indicators where there were many tied ranks of equal data, the split between categories was adjusted to ensure a 'best fit' of equal numbers,

without splitting areas or centres with the same values.

The disadvantage with equal counts of data is that it does not take into account the distribution of the data, and categories can be created with very different ranges of variation between the highest and lowest values. This should be taken into consideration when comparing areas or centres in different categories within indicators.

In Maps 8 and 10–12, data are mapped by renal centre. The renal centres are displayed as coloured circles placed on their location in England. As renal centres are generally located in larger towns and cities and have satellite services elsewhere, a map displaying the location of all main renal centres and satellite dialysis units is shown on page 19. If all of the main renal centres and satellite dialysis units had been included in the maps for these four indicators, the impact of each visualisation would have been reduced.

The classification is shaded from light maroon (lowest value) to dark maroon (highest value) on both the column charts and maps. The ranges and their shading do not indicate whether a high or low value represents either good or poor performance.

The charts have been originally produced in Microsoft Excel 2007 and the maps originally created using MapInfo Professional 10.5.

Standardisation

Standardisation allows like to be compared with like, by making sure that differences in the number of events (e.g. deaths or infections) observed in two or more populations are not due to differences in the age and sex profile between the different populations. (For example, suppose population A has a higher death rate than population B. However, if population A also has a higher proportion of older people, then we would expect there to be more deaths and it would be misleading to infer that people are dying at a faster rate in population A than in population B.) The two main methods of standardisation are:

- directly standardised rates;
- indirectly standardised rates (or ratios).

Directly standardised rates adjust for differences in age and sex distribution by applying the observed rates (e.g. of disease) for each age-band in the study area (e.g. the PCT) to a standard population structure (in this case, the European Standard population) to obtain a weighted average rate.

Indirectly standardised ratios adjust for the differences in age and sex distribution by applying the observed rates (e.g. of RRT) for each age-band/sex in a standard population (in this case, England) to the population of the same age-groups in the study area (e.g. the PCT). The observed cases in the local area are divided by these expected numbers to provide a ratio. A standardised ratio closer to 1 indicates that the area's rate was as expected if the age/sex rates found in the England population applied to the PCT area's population structure. Indirect standardisation has been used for the indicators in Maps 6, 7 and 14.

Confidence intervals

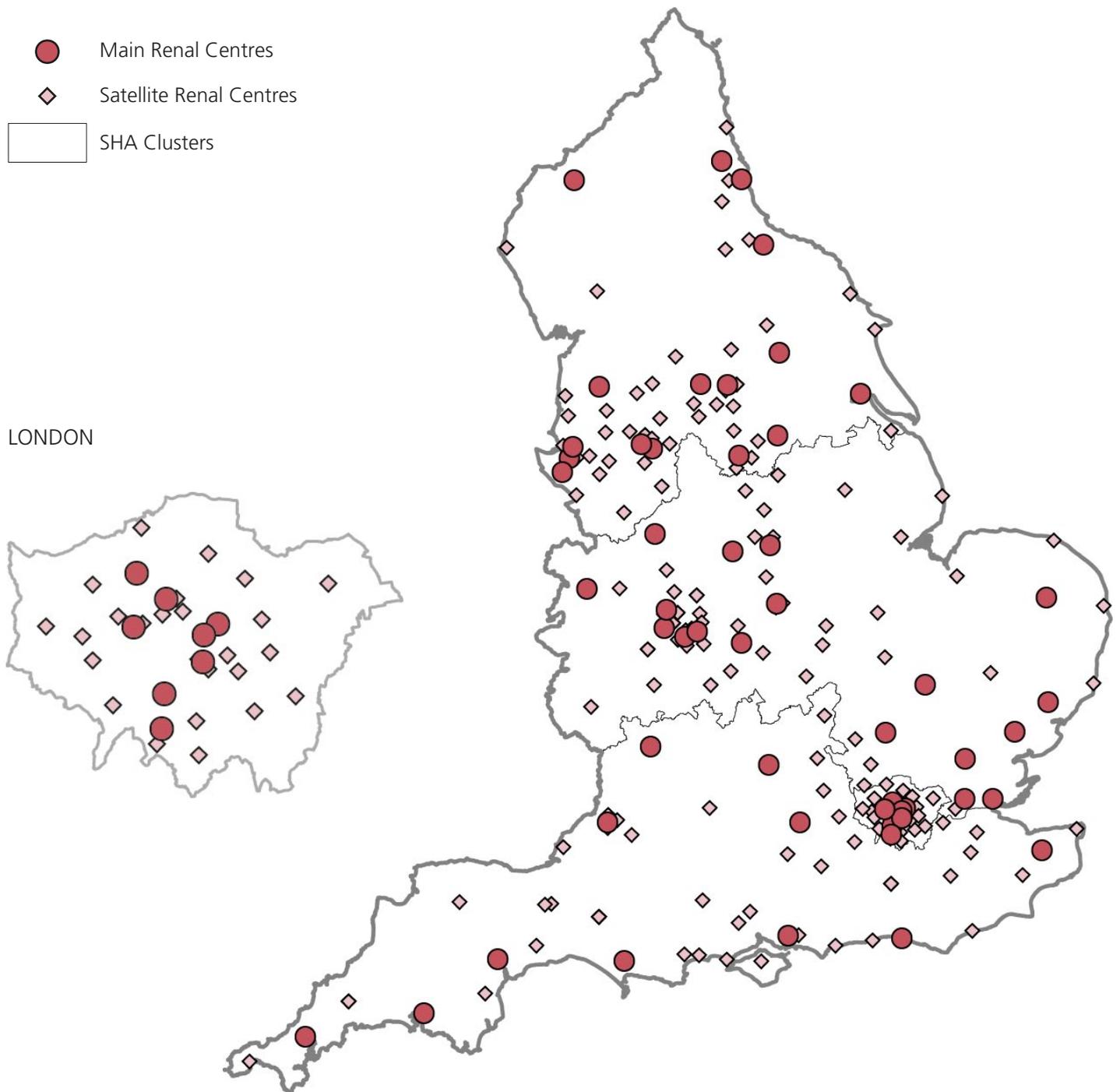
Some of the indicators have error terms, referred to as confidence intervals, associated with them to give an indication of the level of uncertainty of the calculation. Statistical uncertainties usually arise because the indicators are based on a random sample of finite size from a population of interest. Confidence intervals are used to assess what would happen if we were to repeat the same study, over and over, using different samples each time. The precise statistical definition of a 95% confidence interval states that, on repeated sampling, 95 times out of 100 the true population value would be within the calculated confidence interval range and for 5 times out of 100 the true value would be either higher or lower than the range. Where these confidence intervals have been calculated for indicators in the Kidney Care Atlas, they are displayed on the columns of the relevant charts as a series of vertical lines intersecting the top of each column. The smaller the confidence interval, the more stable the indicator; a larger number of events leads to a smaller interval.

Exclusions

For each of the indicators mapped to PCT geography (Maps 1–4, 6, 7 and 14–18), the calculation of the full range of variation is given in the accompanying commentaries; in addition, the range has then been calculated from which the five highest values and the five lowest values have been excluded. This is because “outliers” could be the result of errors in data management, e.g. some data may not have been returned or events may have been recorded twice. This exclusion was originally suggested by Professor Sir Mike Richards for Atlas 1.0, and Right Care has continued to use the “Richards heuristic” in Atlas 2.0, the Child Health Atlas and the Kidney Care Atlas.

There are no exclusions for the indicators mapped by SHA (Map 13), renal network (Map 9), renal centre (Maps 8 and 10–12), and country (Map 5).

FIGURE MCP.1: MAP TO SHOW THE LOCATION OF MAIN RENAL CENTRES AND THEIR SATELLITE DIALYSIS UNITS (AGAINST SHA BOUNDARIES)



Domains in the NHS Outcomes Framework

Underneath the title for each indicator, the domain or domains in the NHS Outcomes Framework 2012/13 relevant to the indicator have been listed. The five domains are as follows:

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

Table S.1: Summary of indicators in the Kidney Care Atlas, showing the range and magnitude of variation before and after exclusions;¹ each indicator has been assigned to one of the following categories – activity, cost, equity, outcome, quality (performance as compared with a standard), and safety.

Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
1	Ratio of reported to expected prevalence of chronic kidney disease (CKD) by PCT 2010/11	0.3–1.4	4.5	0.4–1.0	2.3	Quality
2	Percentage of patients on the chronic kidney disease (CKD) register in whom the last blood-pressure reading, measured in the preceding 15 months, is 140/85 mmHg or less by PCT 2010/11	68.9–81.2	1.2	70.8–78.5	1.1	Quality
3	Percentage of patients on the chronic kidney disease (CKD) register with hypertension and proteinuria who are treated with an angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) by PCT 2010/11	85.7–95.3	1.1	86.9–93.6	1.1	Quality
4	Percentage of patients with diabetes with a diagnosis of proteinuria or micro-albuminuria who are treated with angiotensin converting enzyme (ACE) inhibitors (or A2 antagonists) by PCT 2010/11	81.4–93.5	1.1	84.2–91.7	1.1	Quality
5	Rate of renal replacement therapy (RRT) per 100,000 population by country 2009 ²	53.9–190.4	3.5	Not applicable	Not applicable	Outcome
6	Standardised acceptance ratio (SAR) for incidence of renal replacement therapy (RRT) by PCT 2004–2009	0.4–2.6	7	0.7–1.8	2.6	Quality
7	Standardised prevalence ratio (SPR) of renal replacement therapy (RRT) by PCT 2004–2009	0.5–2.4	4.7	0.8–1.8	2.4	Outcome
8	Proportion (%) of people starting renal replacement therapy (RRT) for established renal failure (ERF) <90 days after presenting to renal services by renal centre 2009	11.5–35.2	3.1	Not applicable	Not applicable	Quality
9	Percentage of incident dialysis patients with definitive access (arterio-venous fistula or graft or peritoneal dialysis catheter) by renal network 2009–2010	42.5–62.3	1.5	Not applicable	Not applicable	Quality

1 For Maps 1–4, 6, 7 and Maps 14–18, at PCT level, the five highest values and the five lowest values have been excluded.

2 Date of data for six (of 26) countries is earlier than 2009 – see Table 5.1, page 31.

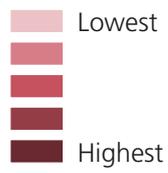
Map no.	Title	Range	Fold difference	Range after exclusions	Fold difference after exclusions	Category of indicator
10	Proportion (%) of prevalent dialysis patients receiving dialysis (haemodialysis and peritoneal dialysis) at home by renal centre 2009	0.0–30.4	Not applicable	Not applicable	Not applicable	Quality
11	Proportion (%) of prevalent dialysis patients receiving haemodialysis at home by renal centre 2009	0.0–11.2	Not applicable	Not applicable	Not applicable	Quality
12	Proportion (%) of prevalent dialysis patients receiving peritoneal dialysis at home by renal centre 2009	0.0–27.5	Not applicable	Not applicable	Not applicable	Quality
13	Rate of kidney transplants from living donors per million population by SHA 2010/11	11.6–22.3	1.9	Not applicable	Not applicable	Activity
14	Standardised pre-emptive transplantation ratio by PCT 2004–2009	0.1–3.5	29	0.2–2.4	11	Outcome
15	Rate of admissions for acute kidney injury (AKI) per 1000 emergency admissions to hospital by PCT 2010/11	1.1–12.2	11	3.3–8.9	2.7	Quality
16	Median length of stay (days) in admissions with a primary diagnosis of acute kidney injury (AKI) by PCT 2010/11	5.0–11.0	2.2	5.0–10.0	2.0	Cost
17	Percentage of respondents in the haemodialysis travel survey with a journey time of 30 minutes or less by PCT 2010	14.3–100.0	7	38.7–95.0	2.5	Equity
18	Percentage of respondents in the haemodialysis travel survey satisfied with their transport service by PCT 2010	64.4–100.0	1.6	66.7–100.0	1.5	Quality

CHRONIC KIDNEY DISEASE

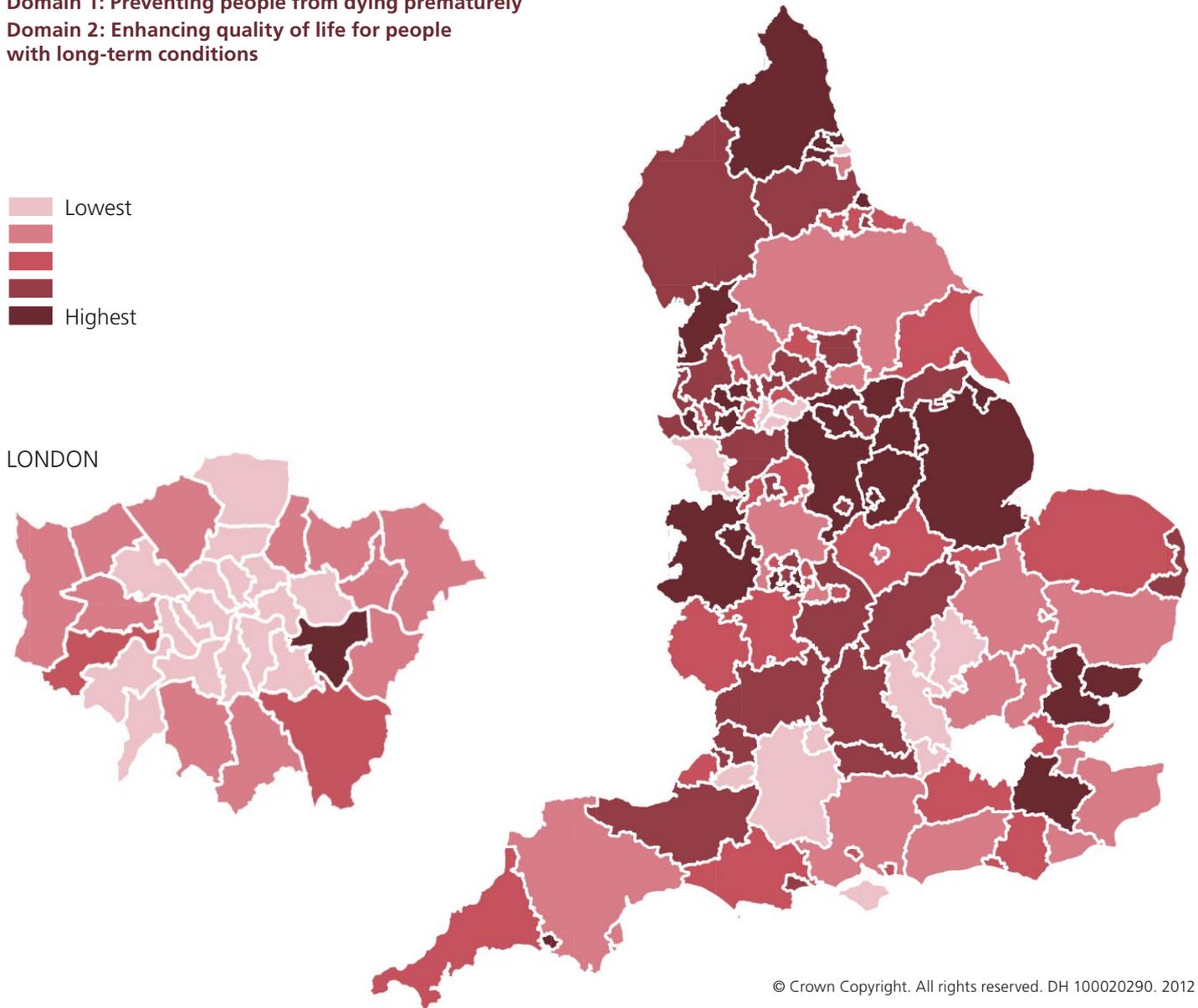
Map 1: Ratio of reported to expected prevalence of chronic kidney disease (CKD) by PCT

2010/11

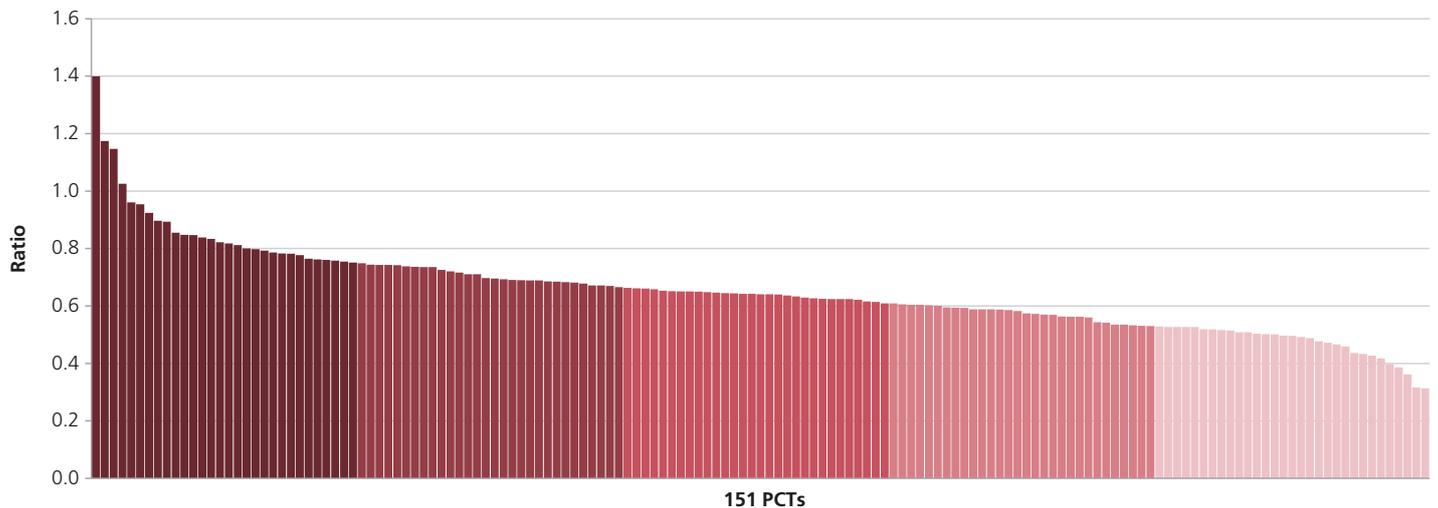
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

The worldwide adoption of a definition for chronic kidney disease (CKD) based on glomerular filtration rate (GFR)¹ together with the introduction of automated reporting of estimated GFR by laboratories resulted in the detection of large numbers of people with previously undetected CKD. In the Quality and Outcomes Framework (QOF), general practitioners are required to establish a register of all patients with CKD. This has enabled the collection of national data on the prevalence of diagnosed CKD in England and Wales.

The majority of patients with CKD have mild disease and are at low risk of progressing to end-stage renal disease. In one study, it has been reported that only 5.9% of those with CKD stage 3 require referral to a nephrologist.² In contrast, even mild reductions in GFR or low levels of albuminuria are associated with a substantial increase in the risk of death due to cardiovascular events.³

Magnitude of variation

For PCTs in England, the ratio of reported to expected prevalence of CKD ranged from 0.3 to 1.4 (4.5-fold variation). When the five PCTs with the highest ratios and the five PCTs with the lowest ratios are excluded, the range is 0.4–1.0, and the variation is 2.3-fold.

This indicator appeared in Atlas 1.0, Map 24 (page 72):

- The ratio of reported to expected prevalence of CKD has increased at both the high and at the low end of the range since 2008/09;
- The degree of variation has increased both before and after exclusions.

There is considerable variation in the ratio of observed versus expected prevalence of diagnosed CKD among PCTs. A similar degree of variation is observed when practices within a PCT are compared (see "Resources", NHS Kidney Care Kidney Disease QOF Toolkit; see also page 72 in Atlas 1.0).

Some of this variation may be accounted for by differences in the prevalence of important risk factors such as age, diabetes, cardiovascular disease and use of nephrotoxic drugs.

Nonetheless, it is likely that most of the variation is due to the variable detection of CKD:

- An excessively high prevalence may result if the diagnosis of CKD is based on a single abnormal GFR (instead of two values $<60 \text{ ml/min/1.73m}^2$, as required by the definition);
- A low prevalence may be due to failure to screen all appropriate patients.

Options for action

The key to reducing unwarranted variation in the prevalence of chronic kidney disease is to improve CKD screening. Screening should comprise:

- Estimated GFR measured on a blood specimen obtained after 12 hours without eating meat;
- Repeat estimated GFR after at least 90 days to confirm an abnormal result;
- Dipstick urinalysis and measurement of urine albumin:creatinine ratio (UACR) to assess albuminuria.

In NICE guidance, it is recommended that patients with the following conditions or treatment regimens should be screened for CKD:

- Diabetes;
- Hypertension;
- Cardiovascular disease;
- Structural renal tract disease (renal calculi or prostatic hypertrophy);
- Multisystem diseases with potential kidney involvement, e.g. systemic lupus erythematosus (SLE);
- Family history of CKD stage 5 or hereditary kidney disease;
- Chronic treatment with potentially nephrotoxic drugs.

RESOURCES

- NICE Guidance (2008) Early identification and management of chronic kidney disease in adults in primary and secondary care (Clinical Guidelines, CG73). <http://guidance.nice.org.uk/CG73>
- MacGregor MS, Taal MW (2011) Detection, monitoring and management of patients with CKD. Renal Association Clinical Practice Guideline. <http://www.renal.org/Clinical/GuidelinesSection/Detection-Monitoring-and-Care-of-Patients-with-CKD.aspx>
- NICE (2011) Chronic Kidney Disease Quality Standard. <http://www.nice.org.uk/guidance/qualitystandards/chronickidneydisease/ckdqualitystandard.jsp>
- NHS Kidney Care (2012) Kidney Disease QOF Toolkit January 2012. http://www.kidneycare.nhs.uk/_Resourcestodownload-Toolkits.aspx
- NHS Kidney Care (2012) Chronic Kidney Disease Resource Pack. http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Prevention-Toolstohelpyou.aspx

1 National Kidney Foundation (2002) K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis* 39: S1-266.

2 McIntyre, NJ, Fluck, RJ, McIntyre, CW et al (2012) Treatment needs and diagnosis awareness in primary care patients with CKD. *Br J Gen Pract* 62; e227-e232(6).

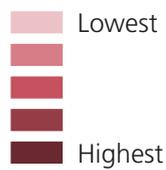
3 van der Velde, M, Matsushita, K, Coresh, J et al (2011) Lower estimated glomerular filtration rate and higher albuminuria are associated with all-cause and cardiovascular mortality. A collaborative meta-analysis of high-risk population cohorts. *Kidney Int* 79: 1341-1352.

CHRONIC KIDNEY DISEASE

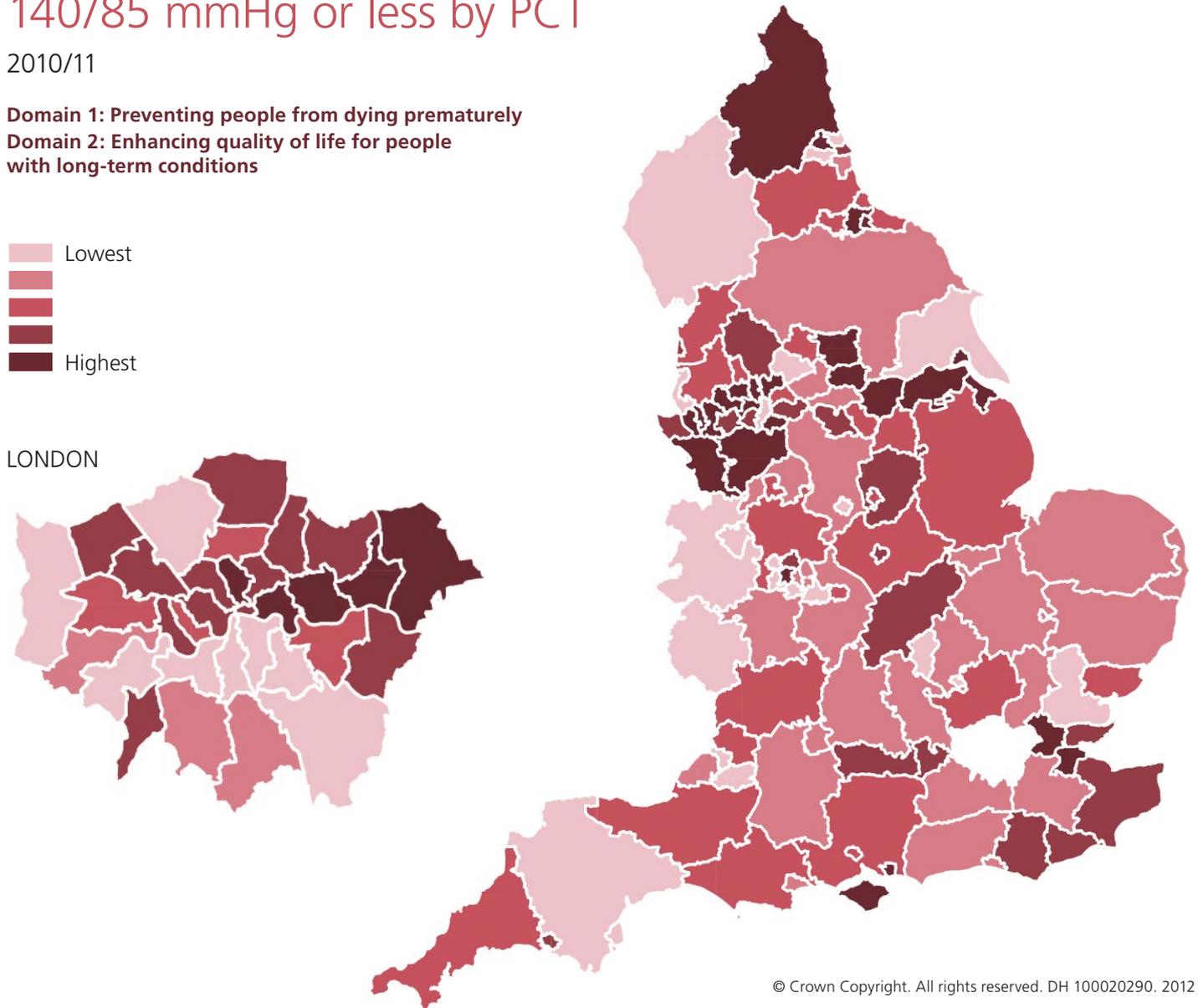
Map 2: Percentage of patients on the chronic kidney disease (CKD) register in whom the last blood-pressure reading, measured in the preceding 15 months, is 140/85 mmHg or less by PCT

2010/11

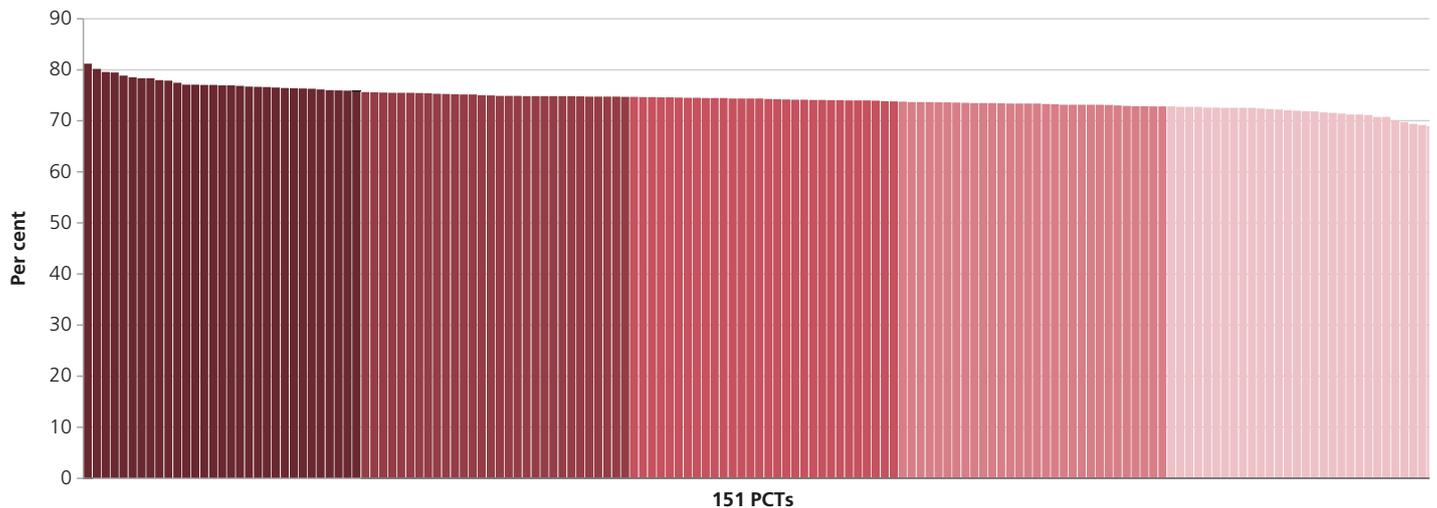
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

The chronic kidney disease (CKD) register includes all people with CKD stages 3, 4 and 5 as coded by GP practice. Treatment of hypertension in people with CKD has been shown to reduce the progression of disease and in high-risk patients it may also reduce the risk of cardiovascular events. The degree of benefit obtained may vary with patient demographics (e.g. age and ethnicity) and the underlying cause of CKD (e.g. diabetic nephropathy).

NICE has suggested the following target blood pressures:

- › For CKD patients without proteinuria, 120–130 mmHg systolic and 60–80 mmHg diastolic;
- › For CKD patients with proteinuria, <130 mmHg systolic and <80 mmHg diastolic.

There is evidence to suggest that both over- and under-treatment of blood pressure is associated with adverse outcomes; therefore, meeting these targets can be difficult. The Quality and Outcomes Framework (QOF) indicator for measuring and managing hypertension in CKD reflects these difficulties and sets a target blood pressure of 140/85 mmHg or less, and an audit standard achievement rate of 40–70%.

Magnitude of variation

For PCTs in England, the percentage of patients on the CKD register in whom the last blood-pressure reading, measured in the preceding 15 months, is 140/85 mmHg or less ranged from 68.9% to 81.2% (1.2-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 70.8–78.5%, and the variation is 1.1-fold.

The majority of PCTs reach between 70% and 80% achievement rates, thereby exceeding the upper limit in the audit standard. This would suggest that most PCTs are managing blood pressure in CKD patients to the QOF target. Despite this, one patient with CKD in every five does not appear to have a blood-pressure measurement within target.

In addition, the data available do not:

- › relate to prevalence;
- › give information about exception rates;
- › show how intensely blood pressure is being controlled or with which antihypertensive agents.

Options for action

It is important that blood pressure is adequately monitored and treated in people with CKD. Barriers to treatment need to be identified and addressed including:

- › Ensuring that at-risk patients are screened for CKD, and documented on a register;
- › Educating people with CKD and healthcare professionals involved in their care about the importance of blood-pressure control;
- › Establishing that people with CKD are prescribed appropriate antihypertensive medications and at appropriate doses;
- › Utilising available published data to identify localities where blood-pressure control in CKD patients is less effective to guide the commissioning of resources and services;
- › Reviewing trial data on the effectiveness of blood-pressure control in CKD patients, with particular attention given to different population subgroups, to guide national policy and its implementation via QOF.

RESOURCES

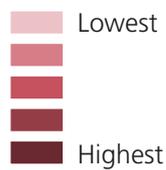
- › NICE Guidance (2011) Hypertension: clinical management of primary hypertension in adults (Clinical Guidelines, CG127). <http://guidance.nice.org.uk/CG127>
- › NICE Guidance (2008) Early identification and management of chronic kidney disease in adults in primary and secondary care (Clinical Guidelines, CG73). <http://guidance.nice.org.uk/CG73>
- › NICE (2011) Chronic Kidney Disease Quality Standard. <http://www.nice.org.uk/guidance/qualitystandards/chronickidneydisease/ckdqualitystandard.jsp>
- › NHS Kidney Care (2012) Kidney Disease QOF Toolkit January 2012. http://www.kidneycare.nhs.uk/_Resourcestodownload-Toolkits.aspx
- › NHS Kidney Care (2012) Chronic Kidney Disease Resource Pack. http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Prevention-Toolstohelpyou.aspx

CHRONIC KIDNEY DISEASE

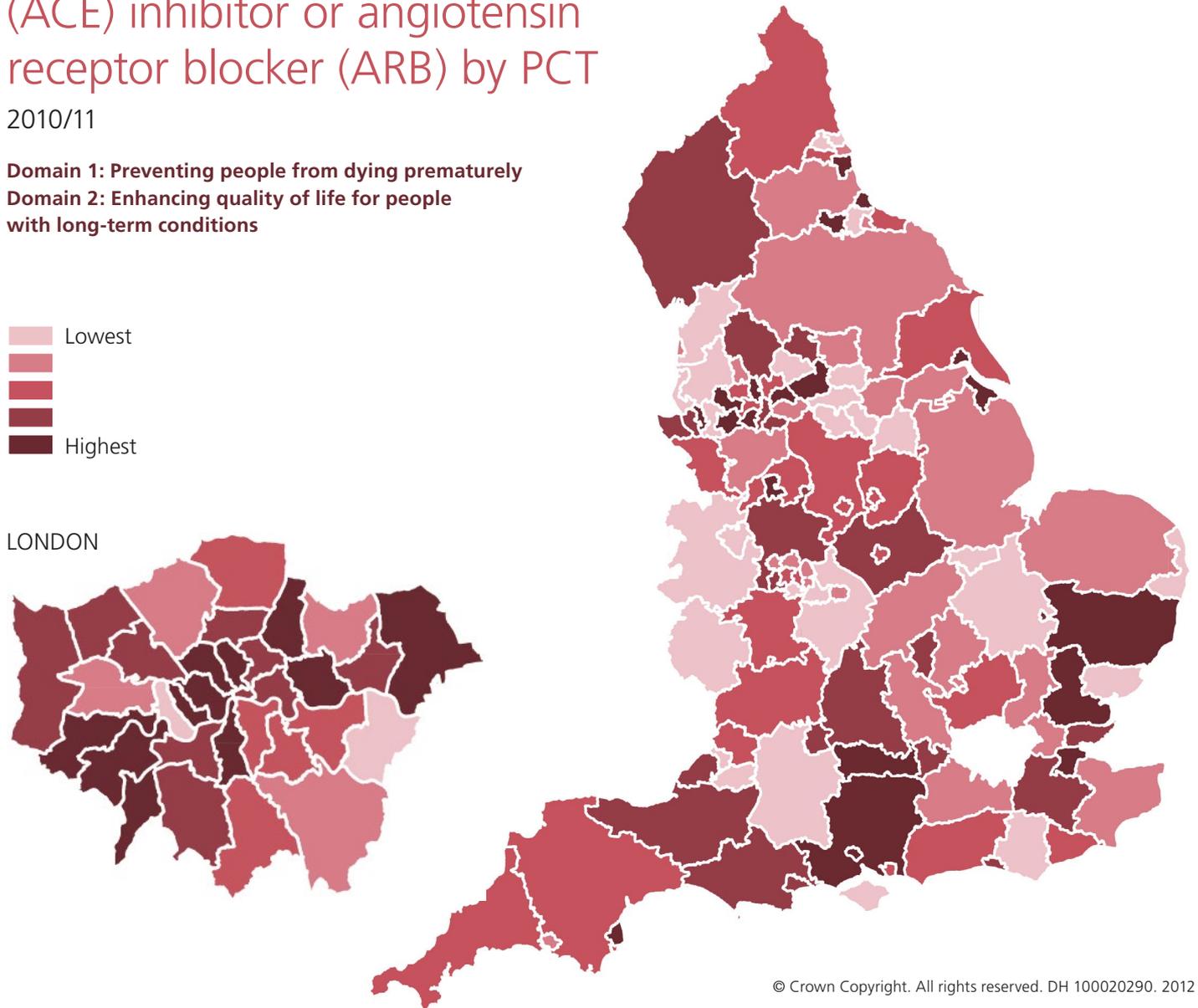
Map 3: Percentage of patients on the chronic kidney disease (CKD) register with hypertension and proteinuria who are treated with an angiotensin converting enzyme (ACE) inhibitor or angiotensin receptor blocker (ARB) by PCT

2010/11

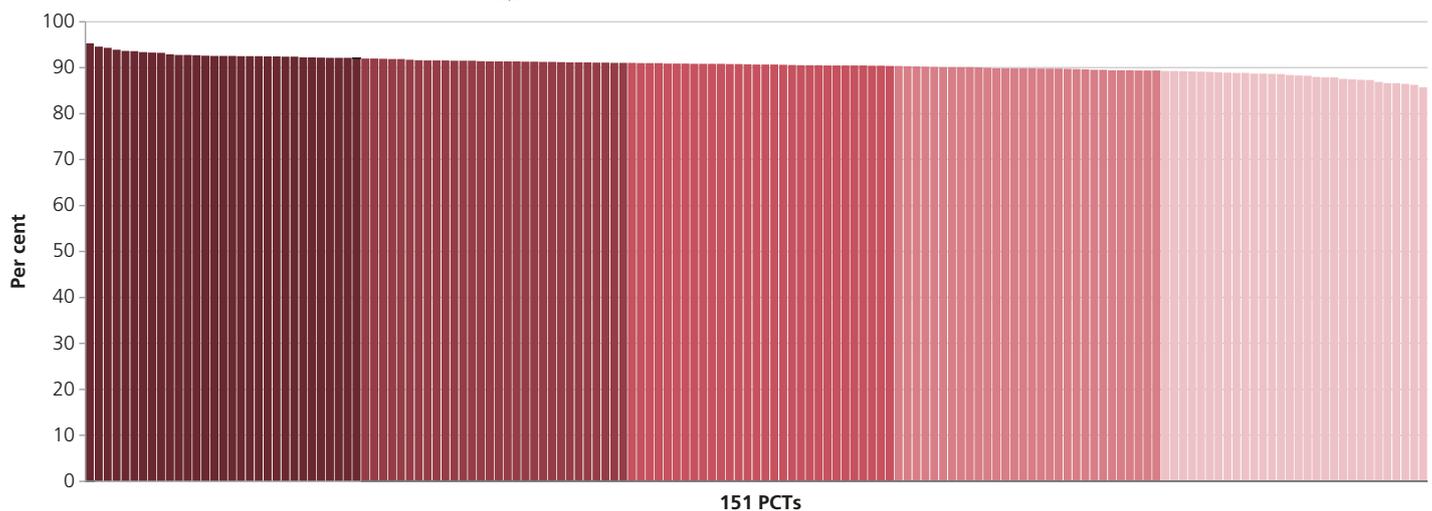
Domain 1: Preventing people from dying prematurely
 Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Patients with chronic kidney disease (CKD) may experience progressive loss of kidney function. This may require renal replacement therapy in the form of dialysis or a transplant. The most effective treatment to prevent decline of kidney function is to control blood pressure. Angiotensin converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs, also known as A2 antagonists) – drugs that block the action of angiotensin – are effective at reducing the damaging effects of blood pressure on kidney function. The prescription of these drugs by general practitioners is incentivised under the Quality and Outcomes Framework (QOF), unless a contra-indication or side-effects are reported.

Patients with proteinuria are most likely to benefit from ACE inhibitors and ARBs. In some patients, these drugs reduce kidney function and so their use must be monitored carefully.

Magnitude of variation

For PCTs in England, the percentage of patients on the CKD register with hypertension and proteinuria who are treated with an ACE inhibitor or ARB ranged from 85.7% to 95.3% (1.1-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 86.9–93.6%, and the variation is 1.1-fold.

The degree of variation in the use of ACE inhibitors and ARBs to treat patients who are on the CKD register is much smaller than the degree of variation in the percentage of patients who have been entered onto the CKD register. This suggests that once patients are identified and registered with CKD, they are likely to receive the treatment recommended and incentivised

under QOF. The payment under QOF reaches a maximum when 80% of registered patients are treated with ACE inhibitors or ARBs. As all PCTs exceed 80%, it would suggest that the QOF incentive is delivering the outcome for which it was designed. However, it should be noted that the QOF does not take into account whether a patient is on an appropriate dose of ACE inhibitor or ARB.

In addition, the data for this indicator do not reveal how many patients with CKD who would benefit from ACE inhibitors and ARBs are not receiving them. In the National Diabetes Audit (NDA) 2009–10, it was found that less than 50% of patients in England with Type 2 diabetes achieve the NICE target for blood-pressure control (see Map 7, page 40, in the Diabetes Atlas). There is no equivalent national audit for CKD.

Options for action

For the whole population of people with CKD to benefit from ACE inhibitors and ARBs, the percentage of patients with CKD entered on the CKD registers of general practitioners needs to increase.

Patients with CKD can be identified relatively simply from data held by pathology laboratories. To improve population health, it is a priority to make better use of these data. Systematic identification and treatment of patients at high risk of progressive kidney damage has been demonstrated to reduce significantly the numbers of patients starting dialysis.¹

RESOURCES

- NHS Information Centre (2011) National Diabetes Audit Executive Summary 2009–2010. http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/National_Diabetes_Audit_Executive_Summary_2009_2010.pdf

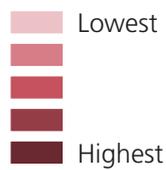
1 Rayner HC, Hollingworth L, Higgins R, Dodds S. Systematic kidney disease management in a population with diabetes mellitus: turning the tide of kidney failure. *BMJ Qual Saf* doi:10.1136/bmjqs-2011-000061

CHRONIC KIDNEY DISEASE

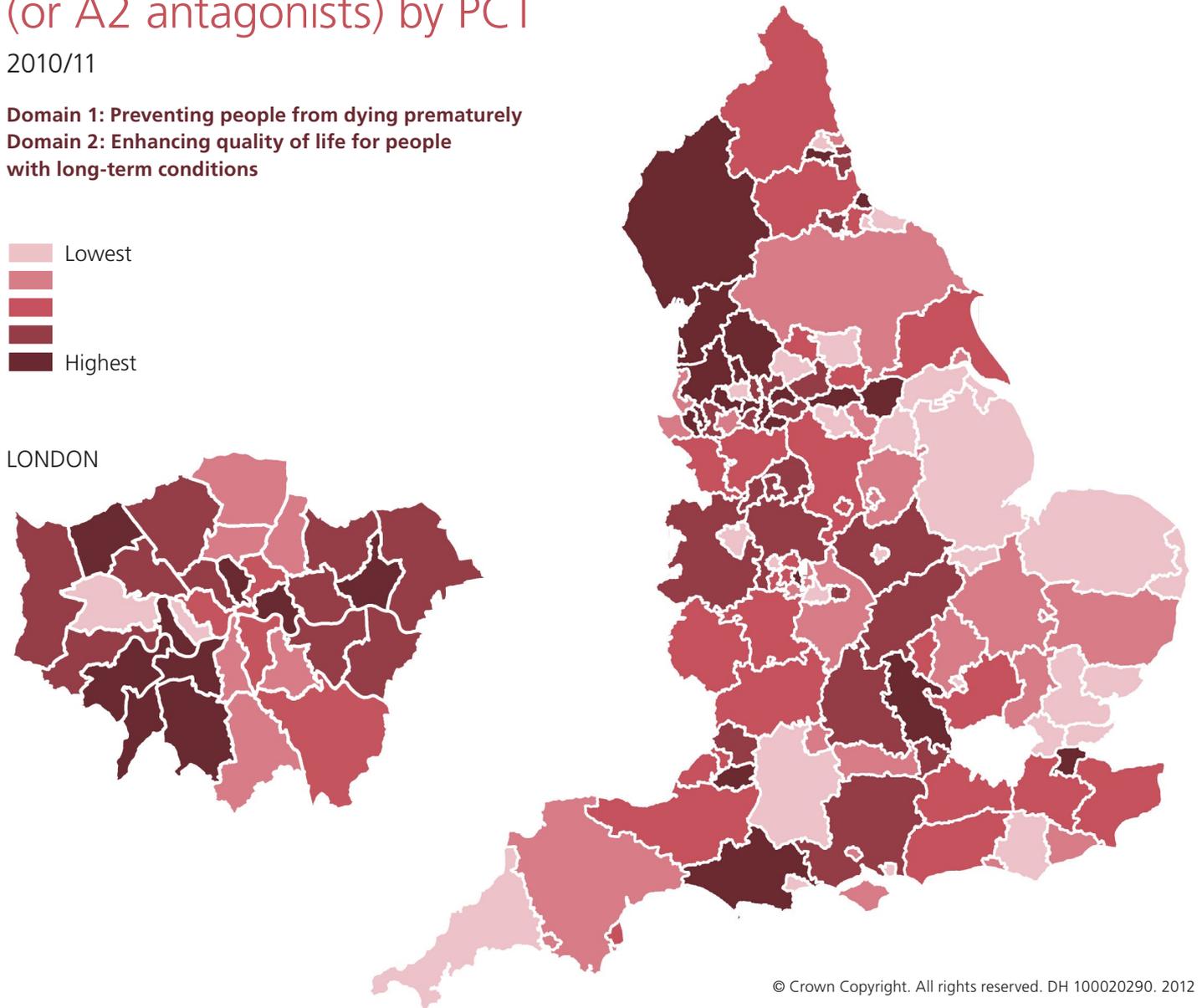
Map 4: Percentage of patients with diabetes with a diagnosis of proteinuria or micro-albuminuria who are treated with angiotensin converting enzyme (ACE) inhibitors (or A2 antagonists) by PCT

2010/11

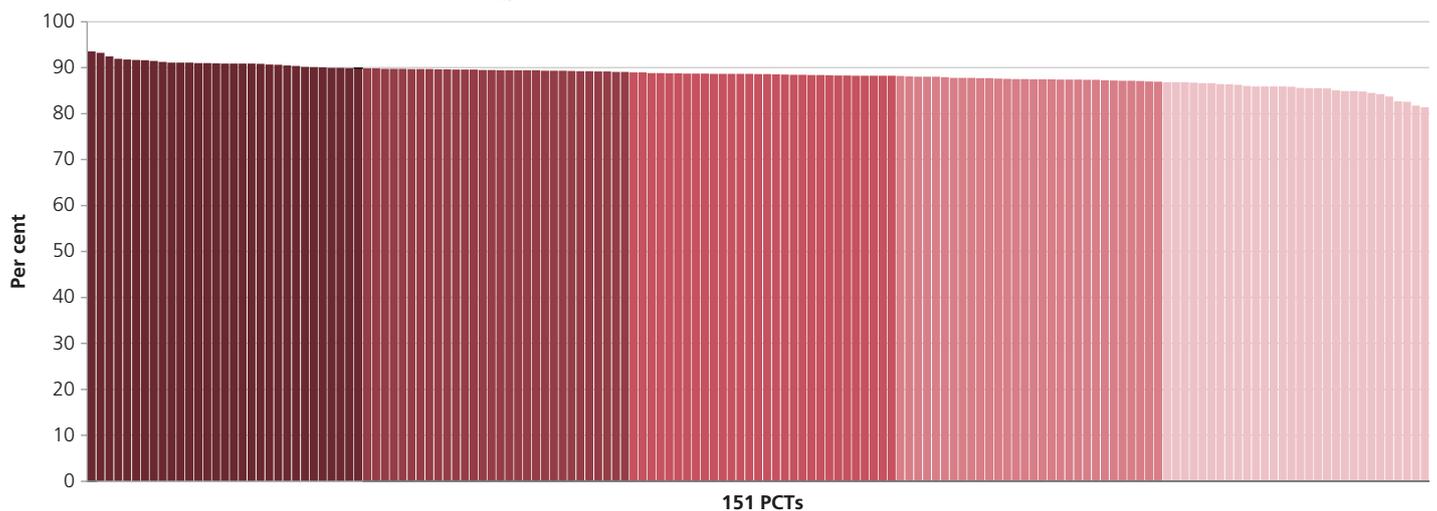
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

End-stage renal disease (ESRD) due to diabetes is rising. Measurement of the urine albumin:creatinine ratio (UACR) can detect early disease and help to slow progression if the renal disease is treated.

NICE identified five studies of renal outcomes in patients with diabetes and the relationship of renal outcomes to blood-pressure control. In patients with Type 2 diabetes, high blood-pressure levels (systolic and/or diastolic blood pressure) were associated with a more rapid decline in renal function than that observed in patients with lower blood-pressure values.

When treatment with angiotensin converting enzyme (ACE) inhibitors was compared with other antihypertensive therapies or with placebo, there was no superiority over other agents on the basis of blood-pressure lowering power or cardiovascular outcomes. However, the evidence did suggest that treatment with ACE inhibitors is related to greater benefits with respect to renal outcomes in patients with Type 2 diabetes when compared with other blood-pressure lowering agents.

Accordingly, NICE recommends that:

- If diabetic nephropathy is confirmed, an ACE inhibitor should be offered with dose titration to maximum dose (unless an ACE inhibitor is not tolerated);
- An A2 antagonist [otherwise known as an angiotensin receptor blocker (ARB)] should be substituted if ACE inhibitors are poorly tolerated;
- Blood pressure should be maintained at <130/80 mmHg if UACR is abnormal.

Magnitude of variation

For PCTs in England, the percentage of patients with diabetes with a diagnosis of proteinuria or micro-albuminuria who are treated with ACE inhibitors (or A2 antagonists) ranged from 81.4% to 93.5% (1.1-fold variation). When the five PCTs with the highest percentages and the five PCTs with the lowest percentages are excluded, the range is 84.2–91.7%, and the variation is 1.1-fold.

The degree of variation observed is fairly modest, suggesting that patients with diabetes with any degree of recorded proteinuria are usually being prescribed an ACE inhibitor or an A2 antagonist (ARB).

However, UACR testing is consistently the least performed and/or recorded annual review check in the National Diabetes Audit (NDA) and so the apparently high level of concordance with NICE guidance may be confounded by under-identification.

On the other hand, confirmation of raised UACR is demanding (see Box 4.1), and there may be over-identification among the patients with diabetes who are tested.

Box 4.1: Confirmation of raised urine albumin:creatinine ratio (UACR)

- If abnormal UACR and no proteinuria/urinary tract infection: repeat test at next two clinic visits and within 3–4 months
- Micro-albuminuria is confirmed if at least one out of two or more results is also abnormal

Options for action

To increase the number of patients with diabetes and ESRD treated appropriately with ACE inhibitors or A2 antagonists (ARBs), it is important to increase the knowledge and understanding of primary care clinicians of:

- how to test for raised UACR;
- how to record the diagnosis of raised UACR.

See also page 57, Case-study 1.

RESOURCES

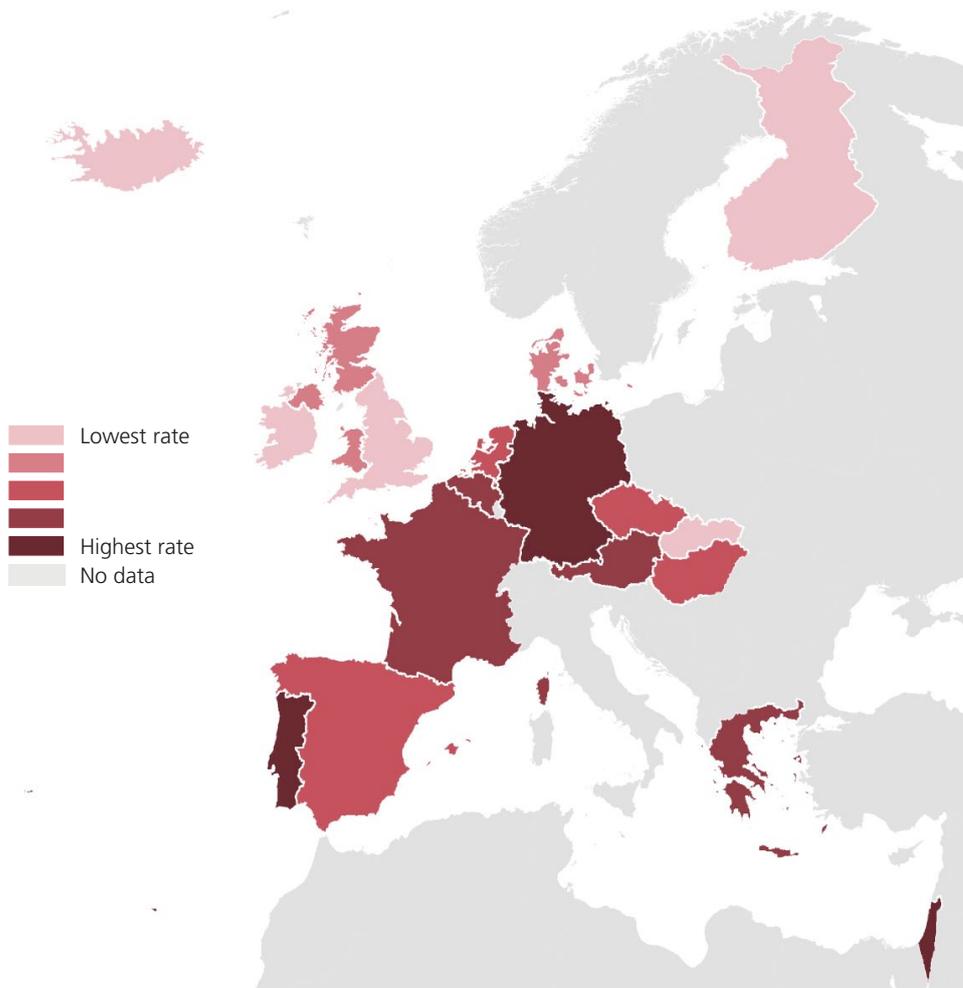
- NHS Information Centre (2011) National Diabetes Audit Executive Summary 2009-2010. http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/National_Diabetes_Audit_Executive_Summary_2009_2010.pdf
- National Collaborating Centre for Chronic Conditions. Type 2 Diabetes. National clinical guideline for management in primary and secondary care (update). <http://www.nice.org.uk/nicemedia/live/11983/40803/40803.pdf>

RENAL REPLACEMENT THERAPY

Map 5: Rate of renal replacement therapy (RRT) per population by country

2009 (for 6 countries, date of the data is not 2009)

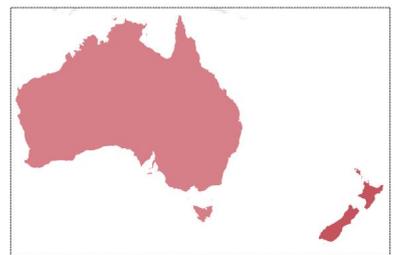
Domain 2: Ensuring quality of life for people with long-term conditions



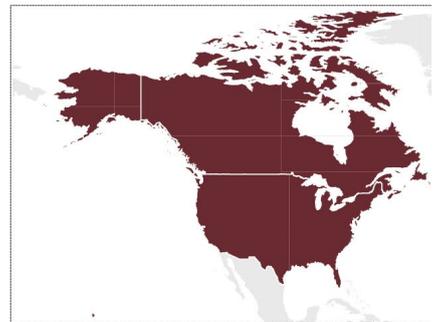
Japan and South Korea



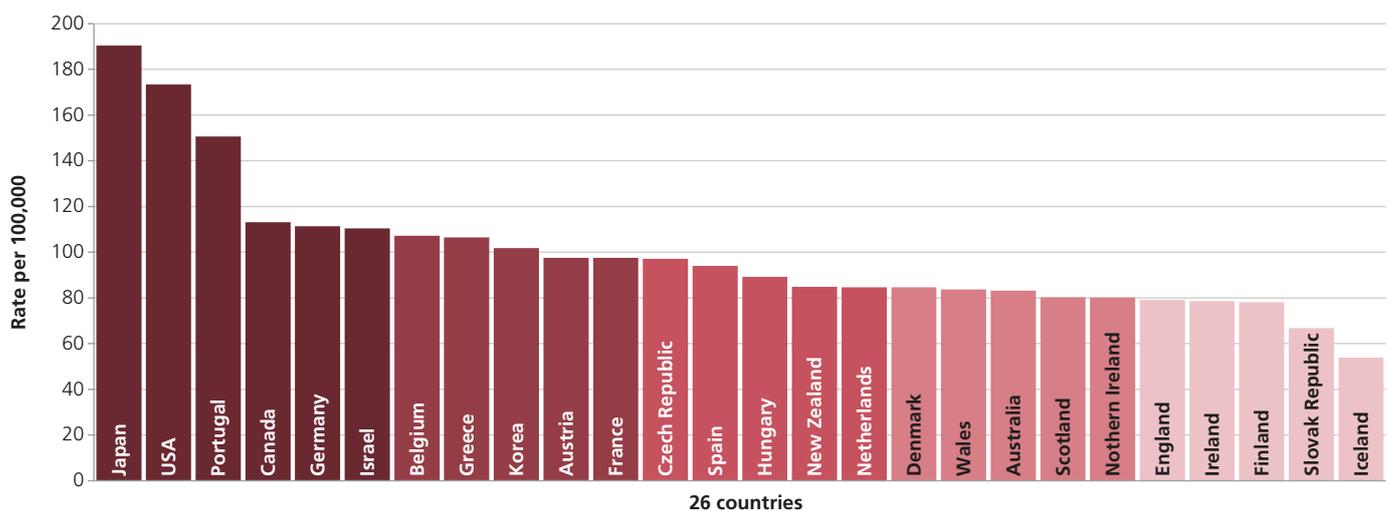
Australia and New Zealand



USA and Canada



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Context

The true prevalence of kidney disease is largely unknown, but there are more cases of kidney disease within certain ethnic groups and in certain countries. Treatment rates for advanced kidney disease with either dialysis or transplantation, known as renal replacement therapy (RRT), vary widely among different countries.

Renal replacement therapy rates reflect differences in: the underlying prevalence of kidney disease; the provision of RRT; survival once RRT has been received; and the threshold for commencement of different RRT modalities.

In a World Health Organization (WHO) report, it was found that 60% of the variation in RRT treatment rates among countries could be explained by differences in gross domestic product (GDP) per capita.¹ Furthermore, the results of an international study showed that the percentage of GDP spent on healthcare and the proportion of dialysis providers that were private for-profit enterprises were also linked to the level of RRT provision.²

Renal replacement therapy is an expensive high-technology treatment. In the USA, RRT accounts for 6.6% of Medicare spending despite only 1% of Medicare patients receiving RRT.³ Decisions about the level of expenditure on RRT considered acceptable need to be made in each country and balanced against the value that the treatment offers. As the economy in any country develops and population life-expectancy improves, these decisions about expenditure become more pressing.

Magnitude of variation

For the countries featured in this indicator, the rate of RRT ranged from 53.9 to 190.4 per 100,000 population (3.5-fold variation). The prevalence rate of RRT in England in 2009 (the last year for which data are available) was 79.1 per 100,000 population, which is similar to that in the other home nations, some of the other Northern European countries and Australia and New Zealand (see Table 5.1). However, it is lower than that in a range of other European countries including Belgium and Germany, and far lower than that in the USA and Japan.

The treatment rate seen in the USA might reflect:

- › higher rates of underlying kidney disease in Black populations;
- › the lack of pre-dialysis for many patients;
- › the high proportion of private for-profit dialysis providers coupled with unrestricted funding for RRT from Medicare – it is noteworthy that 1 in 5 patients withdraw from RRT in the USA.

In the 1990s, there was evidence that: the prevalence of RRT was lower in the UK when compared with other European countries; and in Europe, there were rapidly increasing treatment rates in patient groups who were older and/or who had diabetes, both of which groups previously represented only a small number of patients.⁴

Options for action

It is important to determine the “true” community prevalence of advanced kidney disease requiring RRT to ascertain if unmet need persists in some localities of England.

If unmet need is shown to persist, commissioners and providers need to develop commissioning arrangements that support equity of access for patients with advanced kidney disease.

Commissioners and providers need to encourage shared decision-making about the care patients wish to receive, which includes better education for patients and healthcare professionals.

Finally, it is important for commissioners and providers to support further studies investigating which patients will benefit most from RRT.

RESOURCES

- › NHS Kidney Care. My Kidney Care Plan. http://www.kidneycare.nhs.uk/resources/my_kidney_care_plan/
- › NIHR Health Services and Delivery Research (HS&DR) programme. HS&DR Project – 09/2000/36. A national study of practice patterns in UK renal units in the use of dialysis and conservative kidney management to treat people aged 75 years and over with chronic kidney failure (CKD5). <http://www.netssc.ac.uk/hedr/projdetails.php?ref=09-2000-36>

Table 5.1: Rate of renal replacement therapy (RRT) per 100,000 population for 26 countries, including England, 2009 (unless stated otherwise)

Country	RRT rate	Country	RRT rate	Country	RRT rate
Japan	190.4 (2003)	Austria	97.5	Australia	83.2
USA	173.4	France	97.5	Scotland	80.3
Portugal	150.6	Czech Republic	97.1	Northern Ireland	80.2
Canada	113.1	Spain	94.0 (2008)	England	79.1
Germany	111.3 (2006)	Hungary	89.2	Ireland	78.6
Israel	110.4	New Zealand	84.9	Finland	78.1
Belgium	107.2 (2007)	The Netherlands	84.7	Slovak Republic	66.8 (2005)
Greece	106.5	Denmark	84.6	Iceland	53.9
Korea	101.8 (2008)	Wales	83.7		

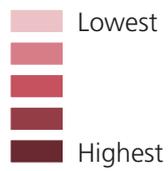
- 1 White SL, Chadban SJ, Jan S et al (2008) How can we achieve global equity in provision of renal replacement therapy? *Bull World Health Organ* 86; 229-237.
- 2 Caskey FJ, Kramer A, Elliott RF et al (2011) Global variation in renal replacement therapy for end-stage renal disease. *Nephrology Dialysis Transplantation* 26; 2604-2610.
- 3 Blagg CR (2011) Preface. *Hemodialysis International* 15; 303-305.
- 4 Stengel B, Billon S, van Dijk P et al (2003) Trends in the incidence of renal replacement therapy for end-stage renal disease in Europe, 1990-1999. *Nephrology Dialysis Transplantation* 18; 1824-1833.

RENAL REPLACEMENT THERAPY

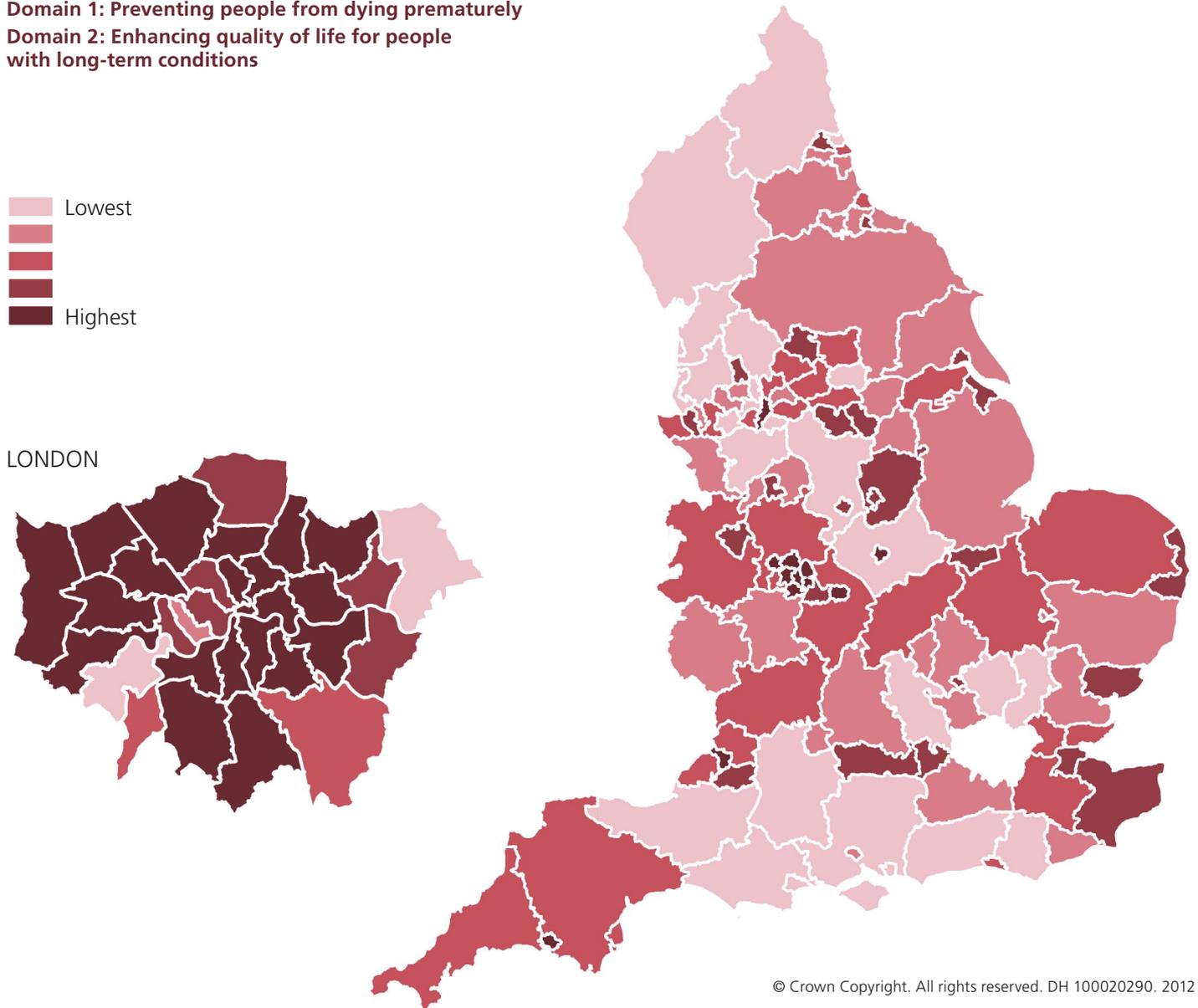
Map 6: Standardised acceptance ratio (SAR) for incidence of renal replacement therapy (RRT) by PCT

Indirectly standardised ratio, adjusted for age and sex 2004–2009

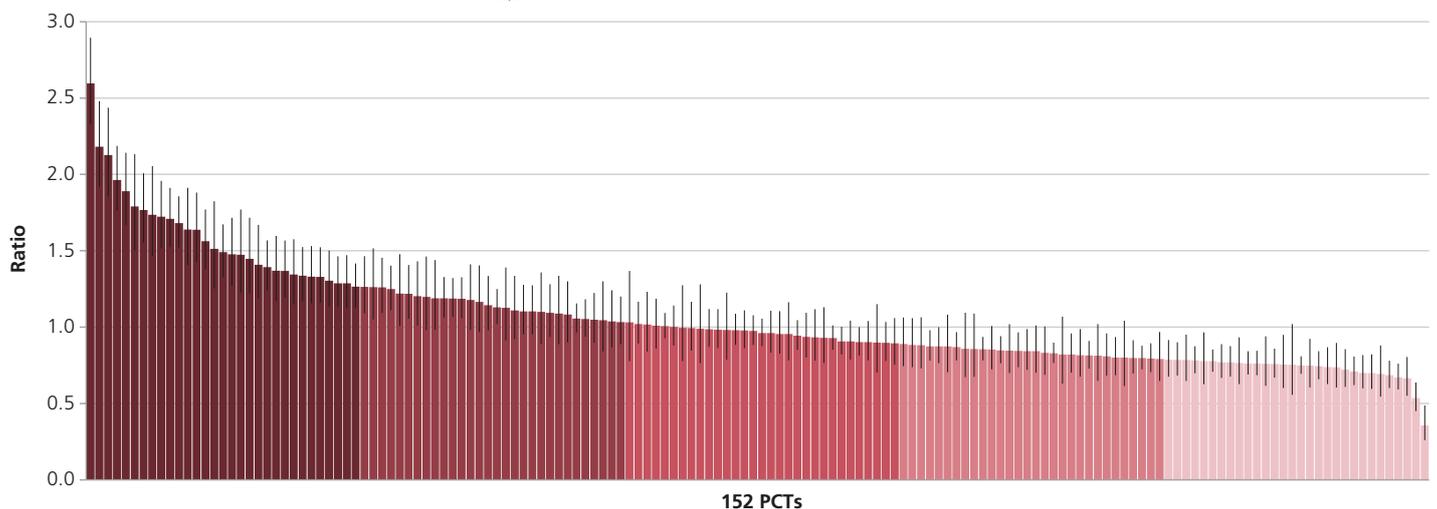
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

When chronic kidney disease (CKD) progresses to end-stage renal disease (ESRD), renal replacement therapy (RRT) considerably improves both longevity and quality of life. However, the cost of RRT is substantial: in countries with developed economies, approximately 1–2% of healthcare expenditure is incurred by the 0.02–0.06% of the population receiving RRT.¹ It is essential that any service provides benefits to the population in an equitable fashion, irrespective of sex, ethnicity, socio-economic status or geographical location.

The data for this indicator describe the effect of geographical location at PCT level on RRT incidence rates [expressed as the standardised acceptance ratio (SAR), i.e. the observed acceptance rate divided by the expected acceptance rate, adjusted for age and sex].

Magnitude of variation

For PCTs in England, the SAR for incidence of RRT ranged from 0.4 to 2.6 (7-fold variation). When the five PCTs with the highest ratios and the five PCTs with the lowest ratios are excluded, the range is 0.7–1.8, and the variation is 2.6-fold.

Although SARs in England have been broadly stable for the period 2006–2009, there are considerable regional variations in the SAR. Of the 152 PCTs:

- 42 PCTs have higher SARs than expected;
- 46 PCTs have lower SARs than expected.

These data have not been adjusted for socio-economic status, ethnicity or co-morbidity. People from lower socio-economic groups are more likely to have CKD² and to progress to established renal failure (ERF).^{3,4} People from ethnic minority groups have higher rates of ERF.⁵ Complex interactions between ethnicity and co-morbidity, such as diabetes, appear to accelerate CKD. Therefore, SARs are expected to be higher in localities with higher rates of social deprivation, greater representation of ethnic minority groups and increased levels of relevant co-morbidities. There is a positive correlation between SAR and the percentage of non-White individuals in a given locality.

However, the number of incident patients depends not only upon the actual incidence of ERF but also on the referral and acceptance policies. The acceptance of older people for RRT

has increased considerably over the years, but simultaneously there have been advances in conservative management pathways, which may lead to a limiting of referral in this population sub-group. Latterly, higher standards of pre-dialysis care are also likely to have had an influence on RRT referral rates.

Options for action

Commissioners and providers need to identify differences in healthcare provision with the help of resources such as the 'Health Inequalities and Chronic Kidney Disease in Adults' report by NHS Kidney Care, and the interactive maps provided by the UK Renal Registry (see "Resources").

As improved data lead to better decision-making, commissioners and providers need to increase their knowledge and understanding of the local population by improving:

- the identification, recording and coding of CKD and co-morbidities (e.g. NHS Kidney Care Kidney Disease QOF toolkit 2011) – early identification will lead to improved patient care through more timely management;
- data accuracy and reporting to the NHS and the UK Renal Registry, which will improve the quality of the analyses that can be conducted, such as the Chronic Kidney Disease PCT profiles, and the UK Renal Registry annual report.

RESOURCES

- NHS Kidney Care (2011) Health Inequalities and Chronic Kidney Disease in Adults. First Edition - May 2011. <http://www.kidneycare.nhs.uk/document.php?o=465>
- UK Renal Registry Interactive Geographical Maps. <http://www.renalreg.com/Maps/maps.html>
- NHS Kidney Care (2012) Kidney Disease QOF Toolkit January 2012. http://www.kidneycare.nhs.uk/_Resourcestodownload-Toolkits.aspx
- Chronic Kidney Disease PCT profiles. http://www.kidneycare.nhs.uk/our_work_programmes/prevention/ckd_pct_profiles/kidney_disease_pct_profiles/
- The Renal Association (2010) UK Renal Registry. The Thirteenth Annual Report. December 2010. <http://www.renalreg.com/Reports/2010.html>
- NICE Guidance (2008) Early identification and management of chronic kidney disease in adults in primary and secondary care (Clinical Guidelines, CG73). <http://guidance.nice.org.uk/CG73>

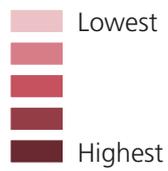
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 - 2 Drey N, Roderick P, Mullee M et al (2003) A population-based study of the incidence and outcomes of diagnosed chronic kidney disease. *Am J Kidney Dis* 42(4); 677-684.
 - 3 Krop JS, Coresh J, Chambless LE et al (1999) A community-based study of explanatory factors for the excess risk for early renal function decline in blacks vs whites with diabetes: the Atherosclerosis Risk in Communities study. *Archives of Internal Medicine* 159(15); 1777-1783.
 - 4 Merkin SS, Coresh J, Roux AV et al (2005) Area socioeconomic status and progressive CKD: the Atherosclerosis Risk in Communities (ARIC) Study. *Am J Kidney Dis* 46(2); 203-213.
 - 5 Gujral J, Burden A, Iqba J et al (1997) The prevalence of chronic renal failure in known diabetic and non-diabetic White Caucasians and South Asians. *Practical Diabetes International* 14(3); 71-74.

RENAL REPLACEMENT THERAPY

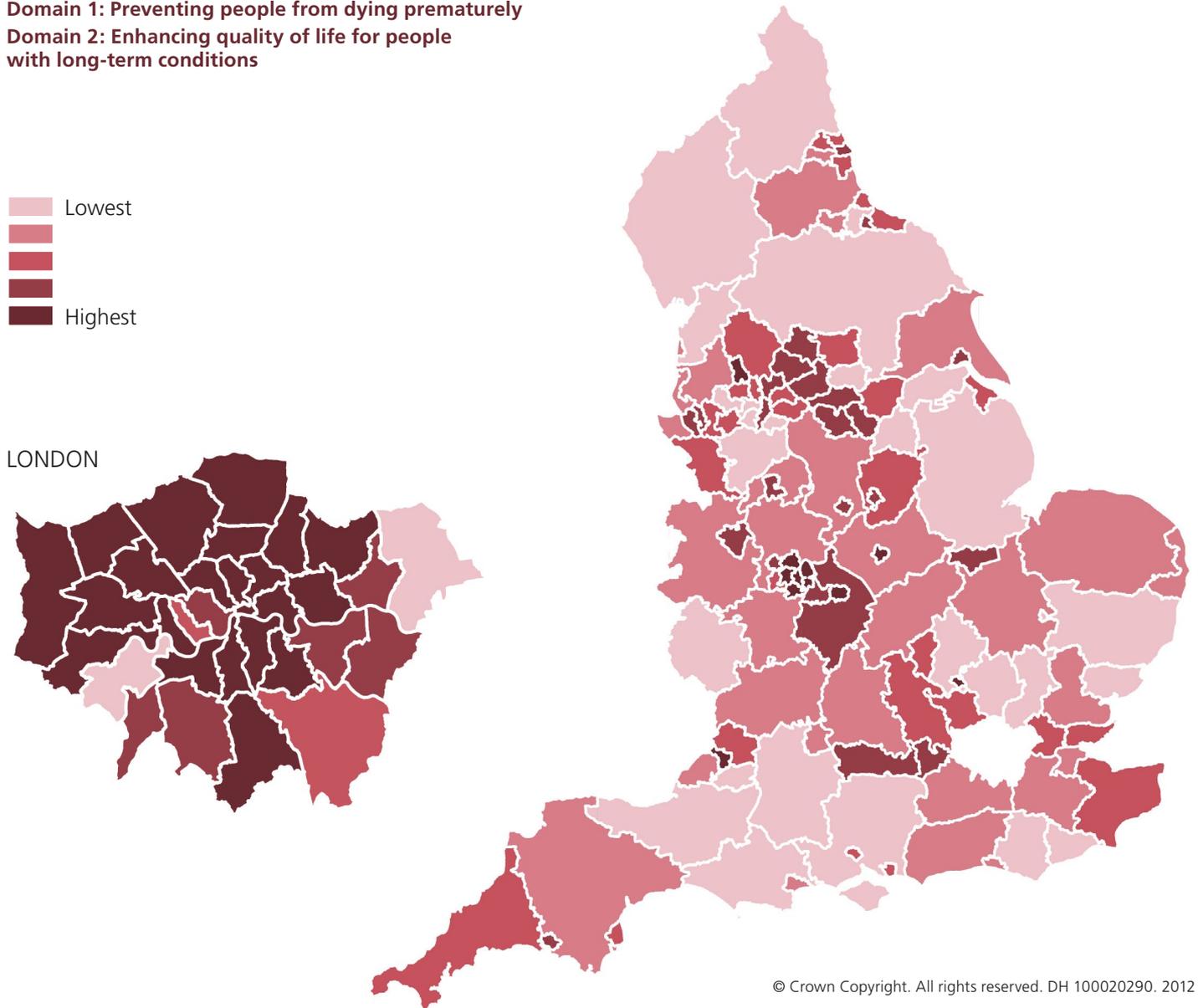
Map 7: Standardised prevalence ratio (SPR) of renal replacement therapy (RRT) by PCT

Indirectly standardised ratio, adjusted for age and sex 2004–2009

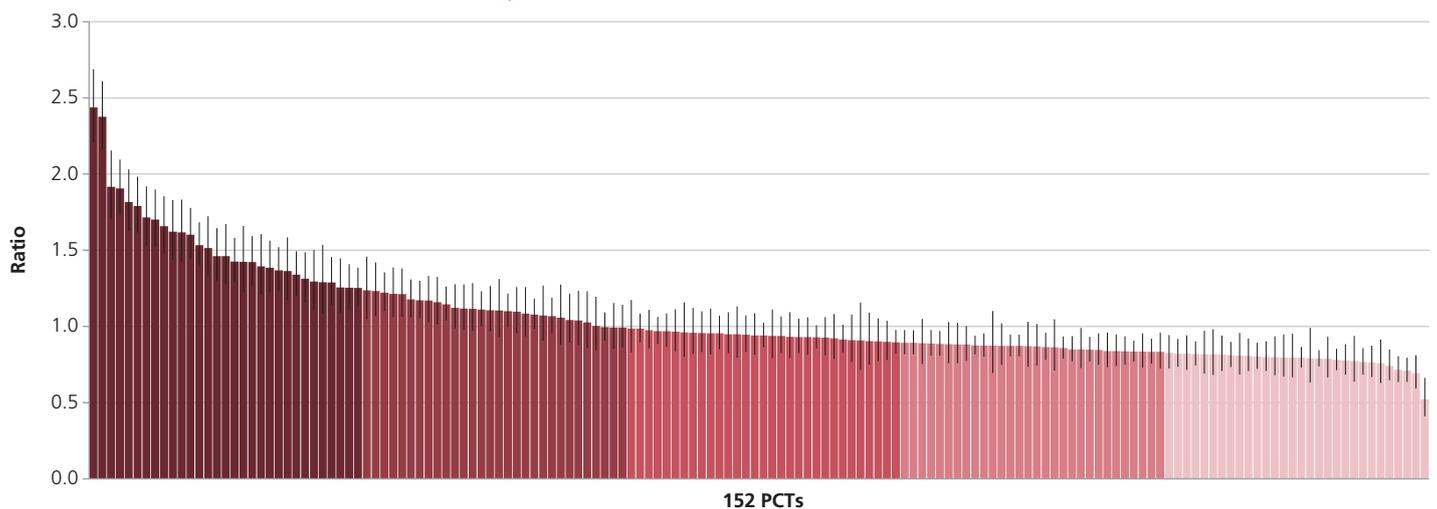
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Chronic kidney disease affects 5–10% of people in the UK,¹ although the condition reaches end-stage renal disease (ESRD) in less than 1% of the UK population. Each year in the UK, there has been a steady increase of 3–4% in the number of patients receiving renal replacement therapy (RRT) for treatment of ESRD.²

Analyses of prevalent RRT patients can support clinicians and policy-makers in planning future RRT requirements. It is important:

- › to understand the variation in numbers of prevalent patients at a national, regional and renal centre level as part of this planning process;
- › to guide where resources should be focused to improve equity of provision of RRT in England.

Magnitude of variation

For PCTs in England, the standardised prevalence ratio (SPR) of RRT ranged from 0.5 to 2.4 (4.7-fold variation). When the five PCTs with the highest ratios and the five PCTs with the lowest ratios are excluded, the range is 0.8–1.8, and the variation is 2.4-fold.

Considerable variation in the SPR by PCT can be observed. In total, 94 PCTs had an SPR of less than 1, which suggests that these PCTs have lower than expected numbers of people receiving RRT.

The need for RRT depends on many factors including:

- › social and demographic factors, such as age, sex, social deprivation, and ethnicity;
- › the presence of co-morbidity.

Patients from ethnic minority groups, with higher levels of deprivation or increasing age, are more likely to have renal disease.^{2–5} These factors may also influence survival rates, which in turn affect prevalent numbers. When conducting a comparison of crude prevalence rates by geographical area, it is important to take into account such factors, otherwise the results of comparison can be misleading. It is possible that adjusting for these factors would eliminate some or much of the variation observed. Nonetheless, it is important to consider whether some degree of variation among PCTs could be the result of a lack of services or low referral rates.

Options for action

To determine whether the degree of variation observed is real, it is necessary to adjust for the socio-demographic factors mentioned above. This can be achieved by sending timely and accurate data returns to the UK Renal Registry (UKRR), which cover all patients receiving RRT within a renal centre.

Any variation that remains unexplained can be investigated in depth, particularly by addressing the questions shown in Box 7.1.

Box 7.1: Investigation of unexplained variation in the SPR

- › Incidence rates of RRT: Are these lower than expected? Are prevalence rates low as a reflection of low uptake rates?
- › Survival rates for patients receiving RRT and for the PCT population: Do these compare favourably with rates in other PCTs? Does your renal centre have significantly higher death rates thereby reducing prevalent RRT numbers?
- › Renal centre facilities: Is there capacity to accommodate appropriate numbers of patients to the end-stage programme?

It is essential that non-nephrology physicians in primary and secondary care are made aware of CKD guidelines and resources to ensure that:

- › patients are referred in a timely and appropriate manner to renal services;
- › there is equity of access to RRT for all in need.

RESOURCES

- › The Renal Association. UK Renal Registry. <http://www.renalreg.com>
- › UK Renal Registry Interactive Geographical Maps. <http://www.renalreg.com/Maps/maps.html>
- › NHS Kidney Care (2012) Kidney Disease QOF Toolkit January 2012. http://www.kidneycare.nhs.uk/_Resourcestodownload-Toolkits.aspx
- › NHS Kidney Care (2011) Health Inequalities and Chronic Kidney Disease in Adults. First Edition - May 2011. <http://www.kidneycare.nhs.uk/document.php?o=465>

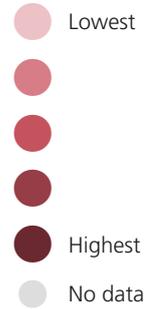
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- 1 Drey N, Roderick P, Mullee M et al (2003) A population-based study of the incidence and outcomes of diagnosed chronic kidney disease. *Am J Kidney Dis* 42; 677-684.
 - 2 The Renal Association & UK Renal Registry (2010) The Thirteenth Annual Report, December 2010, Chapter 2. <http://www.renalreg.com/Reports/2010.html>
 - 3 Kucirka LM, Grams ME, Lessler J et al (2011) Association of race and age with survival among patients undergoing dialysis. *Journal of the American Medical Association* 306; 620-6.
 - 4 Caskey FJ, Roderick P, Steenkamp R et al (2006) Social deprivation and survival on RRT in England and Wales. *Kidney International* 70; 2134-2140.
 - 5 Nitsch D, Burden R, Steenkamp R et al (2007) Patients with diabetic nephropathy on renal replacement therapy in England and Wales. *Quarterly Journal of Medicine* 100; 551-560.

RENAL REPLACEMENT THERAPY

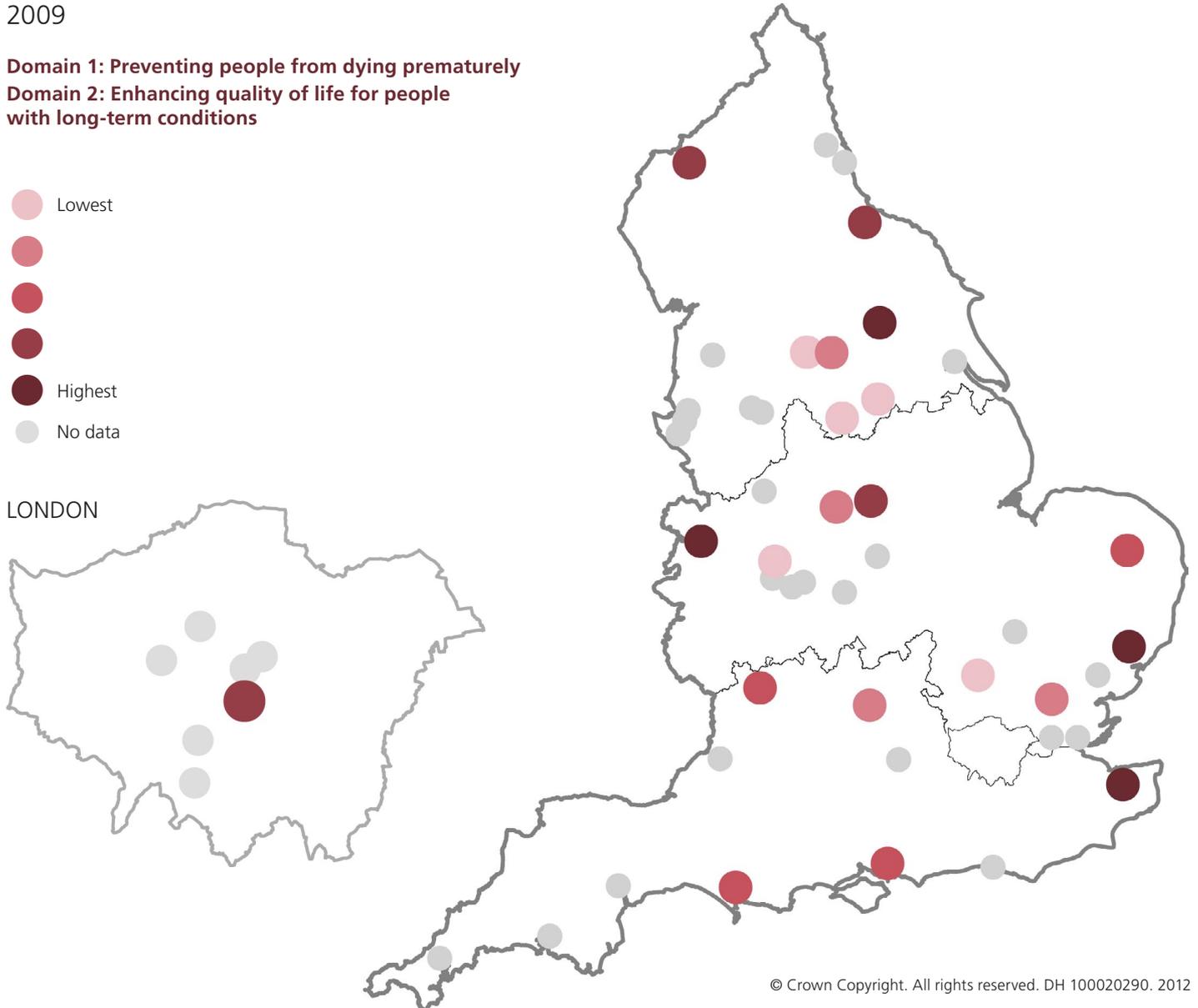
Map 8: Proportion (%) of people starting renal replacement therapy (RRT) for established renal failure (ERF) <90 days after presenting to renal services by renal centre

2009

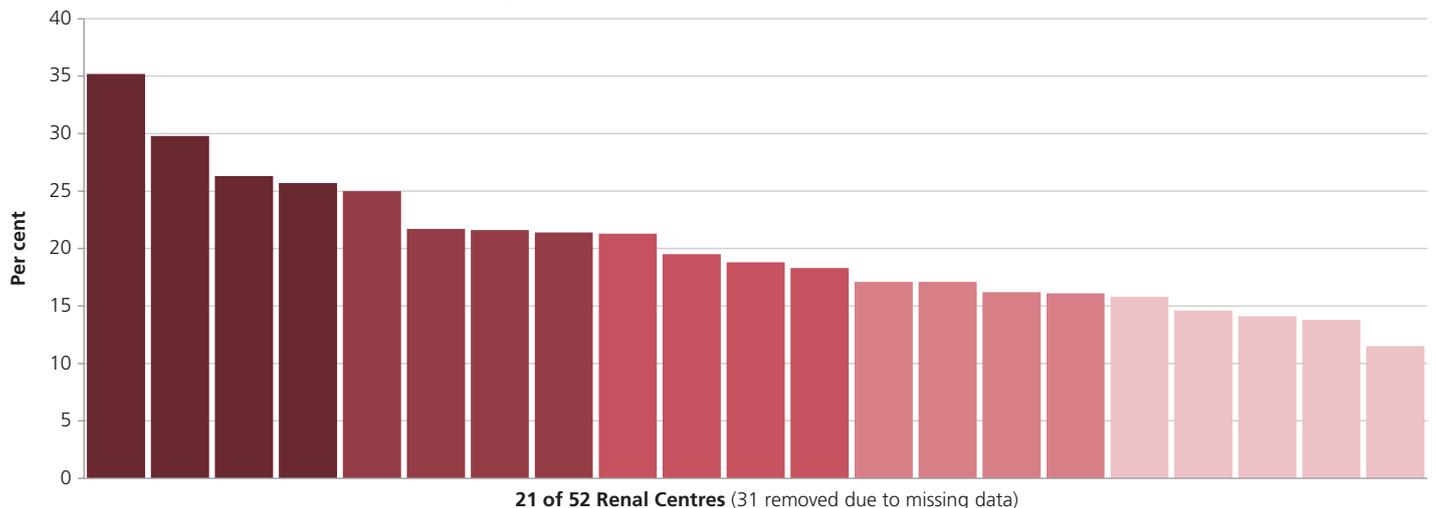
Domain 1: Preventing people from dying prematurely
 Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Patients are referred to nephrologists:

- to determine the cause of kidney disease;
- to institute specific treatments if available;
- to commence management strategies to slow the progression of renal disease;
- to prepare patients for renal replacement therapy (RRT) – dialysis or transplantation.

Late-presenting patients are defined as those first seen by a nephrologist less than 90 days before RRT is commenced.

Late referral and its counterpart, suboptimal dialysis start, have been associated with increased mortality, morbidity, and hospitalisation rates, and lower use of definitive vascular access.^{1,2}

There are several different groups of patients who present late.

1. Patients who present with a rapidly progressive kidney disease for whom earlier referral was not possible and who often have worse outcomes due to the underlying kidney condition.
2. Patients who have not sought medical help previously because there were few symptoms of kidney disease until it was very advanced.
3. Patients known to have progressive kidney disease either in primary care or by another speciality where opportunities are missed for pre-dialysis nephrology care.
4. Patients with an unexpected decline in their renal function despite follow-up.

The results of a recent single-centre study revealed that only 3.9% of referrals could be classified in the avoidable category.³ Patients referred late have less access to transplantation and home-dialysis therapies.

Data for this indicator were available for only 21 of the 52 renal centres in England.

Magnitude of variation

For renal centres in England, the proportion (%) of people starting RRT for established renal failure (ERF) <90 days after presenting to renal services ranged from 11.5% to

35.2% (3.1-fold variation).⁴

Patients with diabetes are less likely to be referred late when compared with patients without diabetes because patients with diabetes have predictable declines in renal function and are usually under the care of another clinician. Therefore, renal centres at which there is a higher proportion of new RRT patients with diabetes are likely to have lower rates of late presentation.

The percentage of patients presenting late has been decreasing over the last 5 years from 27% to 19.4% overall. This is probably due to:

- the widespread reporting of estimated glomerular filtration rate (eGFR);
- the development of specific Renal Association referral guidelines (see “Resources”).

Options for action

For commissioners and providers to reduce the proportion of patients presenting late, it is important:

- To investigate how many patients actually present late in an avoidable manner, and the effect this has on time to transplantation and the use of home-dialysis modalities;
- To ensure that referral for chronic kidney disease and the importance of cardiac disease risk modification are priorities for the education of primary and secondary care professionals;
- To improve general population awareness of kidney disease.

For commissioners, it is also important to commission primary and secondary care services that will encourage and enable the timely referral of appropriate patients.

See also page 59, Case-study 2.

RESOURCES

- NICE Guidance (2008) Early identification and management of chronic kidney disease in adults in primary and secondary care (Clinical Guidelines, CG73). <http://guidance.nice.org.uk/CG73>
- MacGregor MS, Taal MW (2011) Detection, monitoring and management of patients with CKD. Renal Association Clinical Practice Guideline. <http://www.renal.org/Clinical/GuidelinesSection/Detection-Monitoring-and-Care-of-Patients-with-CKD.aspx>

1 de Jager DJ, Voormolen N, Krediet RT, Dekker FW, Boeschoten EW, Grootendorst DC, Group ftNS (2011) Association between time of referral and survival in the first year of dialysis in diabetics and the elderly. *Nephrology Dialysis Transplantation* 26:652-658.

2 Sprangers B, Evenepoel P, Vanrenterghem Y (2006) Late referral of patients with chronic kidney disease: No time to waste. *Mayo Clinic Proceedings* 81; 1487-1494.

3 Udayaraj UP, Haynes R, Winearls CG (2011) Late presentation of patients with end-stage renal disease for renal replacement therapy – is it always avoidable? *Nephrology Dialysis Transplantation* 26; 3646-3651.

4 Data from 31 renal centres are missing.

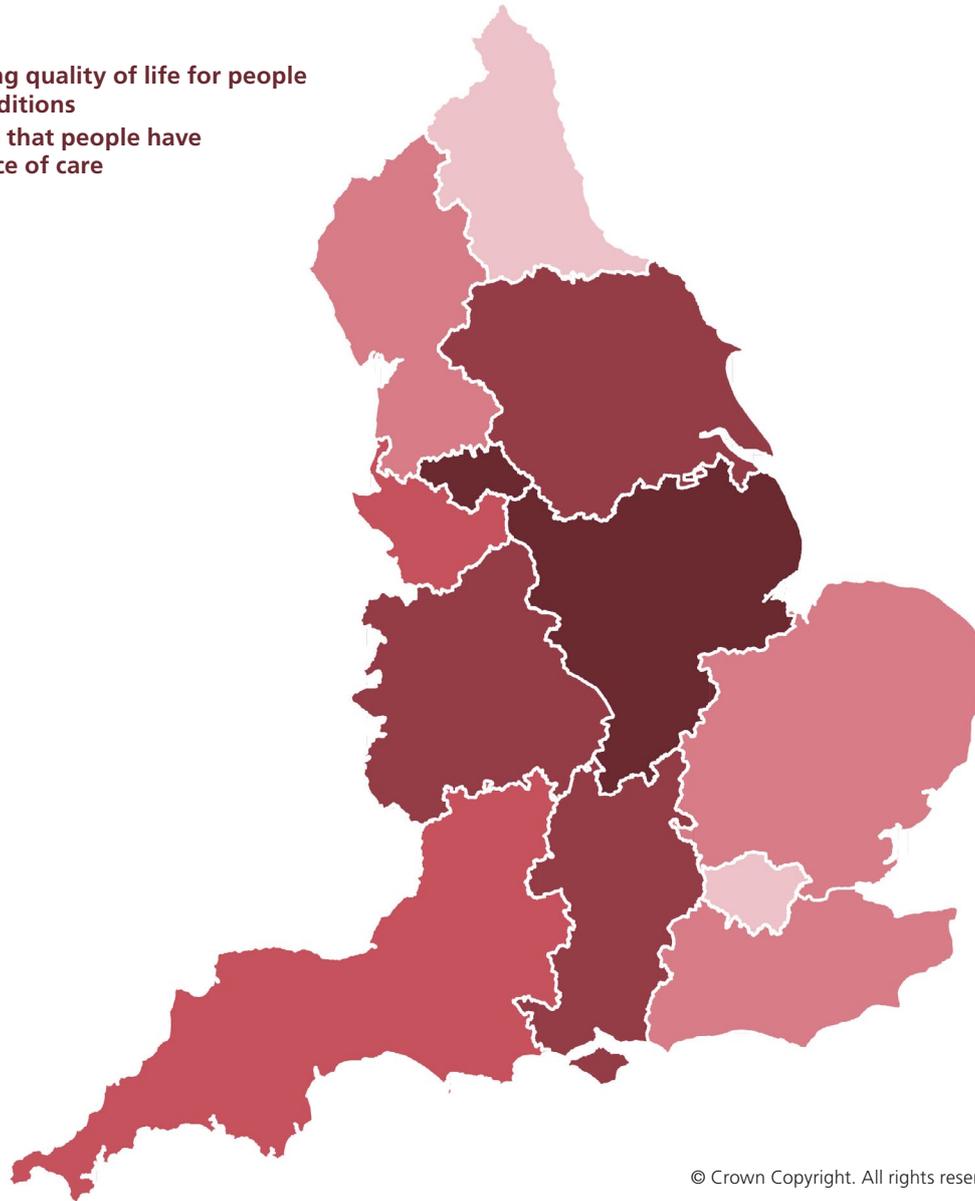
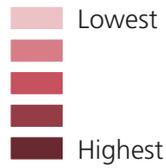
RENAL REPLACEMENT THERAPY

Map 9: Percentage of incident dialysis patients with definitive access (arterio-venous fistula or graft or peritoneal dialysis catheter) by renal network

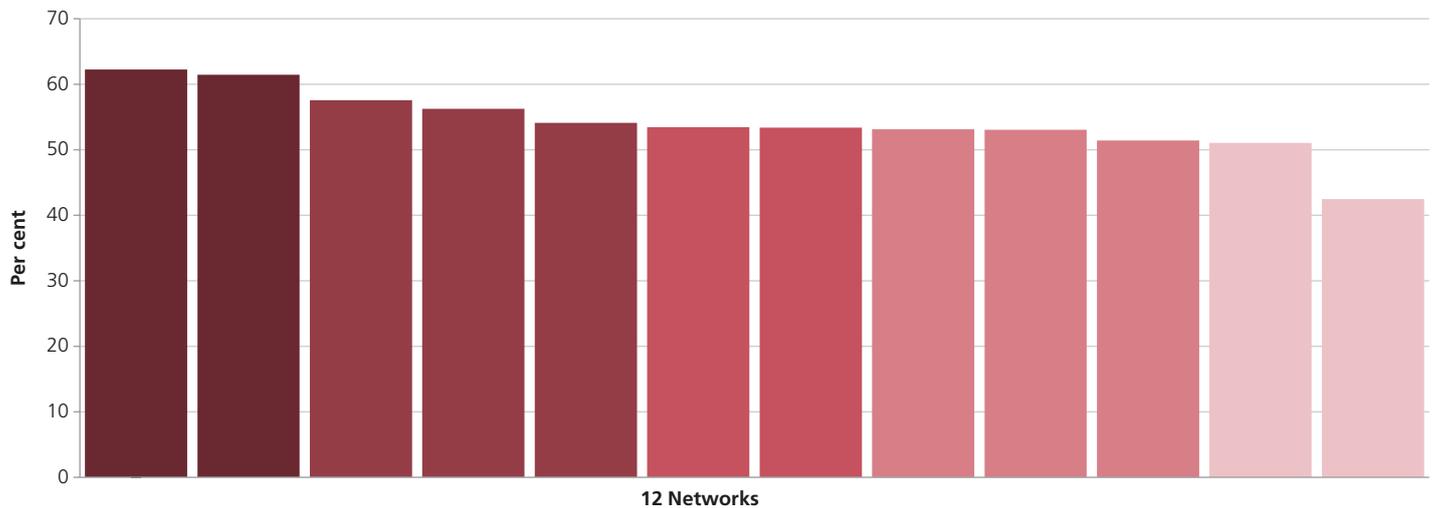
2009–2010

Domain 2: Enhancing quality of life for people with long-term conditions

Domain 4: Ensuring that people have a positive experience of care



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Context

It is generally accepted that haemodialysis via an arterio-venous fistula (AVF) is associated with fewer bloodstream infections and a lower mortality when compared with a dialysis catheter. An AVF thereby improves patient experience, and reduces healthcare costs.

In the UK Renal Association guidelines, it is recommended that 85% of prevalent adult patients on chronic haemodialysis should be receiving treatment via an AVF. Since April 2011, the vascular access used for haemodialysis is part of a differential payment for each dialysis session (a best practice tariff under Payment by Results) to stimulate quality improvement.

Peritoneal dialysis uses an implanted catheter on the abdomen to allow dialysis using the space inside the abdomen for dialysis. This self-administered, home-based treatment allows patients independence and is also associated with a lower rate of bloodstream infections. National policy supports increased uptake of home-based treatments (such as peritoneal dialysis or home haemodialysis with an AVF).

All dialysis centres in England bar two submitted information on the initial access for incident patients commencing renal replacement therapy (RRT). Initial access may be made via an AVF, an arterio-venous graft (AVG; another form of access for haemodialysis) or a peritoneal dialysis (PD) catheter.

A high proportion of patients who start dialysis with definitive access is a marker for effective multi-professional patient dialysis preparation, including:

- › shared decision-making;
- › dialysis-access creation;
- › elective dialysis initiation.

Magnitude of variation

For renal networks in England, the percentage of incident dialysis patients with definitive access (AVF, AVG or PD catheter) ranged from 42.5% to 62.3% (1.5-fold variation).¹ This includes patients who started dialysis at a renal centre where the patient was known for <90 days, a group it is particularly challenging to start effectively on dialysis.

Options for action

For primary care professionals, it is important to identify patients with declining kidney function and direct them to specialist kidney services. This will enable the identification

of patients who need dialysis preparation, and facilitates early decision-making and dialysis-access creation.

Appropriate identification and referral of patients can be improved by commissioners and providers through:

- › investigating variation in presentation at a local level;
- › targeting education at patients, primary care professionals and secondary care providers.

Commissioners also need to consider incentivising:

- › pre-emptive renal transplantation (thereby avoiding the need for dialysis), peritoneal dialysis, and haemodialysis via an AVF through schemes such as CQUIN, which have been effective at rewarding directly best-practice treatment starts in some regions;
- › investment in care pathways for both dialysis and pre-dialysis patients in dialysis-access creation and maintenance through Payment by Results to achieve a high proportion of prevalent chronic dialysis patients using an AVF.

Commissioners and providers need to continue the scrutiny of bloodstream infections (especially those caused by methicillin-resistant and methicillin-sensitive *Staphylococcus aureus* – MRSA and MSSA, respectively) to ensure that NHS Trusts prioritise working with renal centres to reduce the prevalence of haemodialysis catheters as well as improving the care of those patients who have no alternative treatment option other than a haemodialysis catheter.

RESOURCES

- › Healthcare Quality Improvement Partnership (HQIP) National Clinical Audit and Patient Outcomes Programme (NCAPOP) (2011) NCAPOP: National Kidney Care Audit (Vascular Access) 2011 Report. <http://www.hqip.org.uk/ncapop-national-kidney-care-audit-vascular-access-2011-report/>
- › The UK Renal Registry (2005) The Eighth Annual Report. Chapter 6: The National Dialysis Access Survey – preliminary results. <http://www.renalreg.com/Report-Area/Report%202005/chap-06.pdf>
- › Fluck R, Kumwenda M (2011) Vascular Access for Haemodialysis. The Renal Association Clinical Guidelines. <http://renal.org/Clinical/GuidelinesSection/VascularAccess.aspx>
- › Wilkie M, Jenkins S, Shrestha B. Peritoneal Access. The Renal Association Clinical Guidelines. <http://renal.org/Clinical/GuidelinesSection/PeritonealAccess.aspx>
- › NHS Kidney Care. Improving Choice. http://www.kidneycare.nhs.uk/our_work_programmes/preparation/improving_choice/
- › Fistula First. The Fistula First Breakthrough Initiative (USA). <http://fistulafirst.org/>

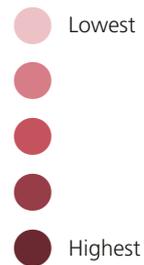
¹ Data were not submitted by two centres within one of the networks.

RENAL REPLACEMENT THERAPY

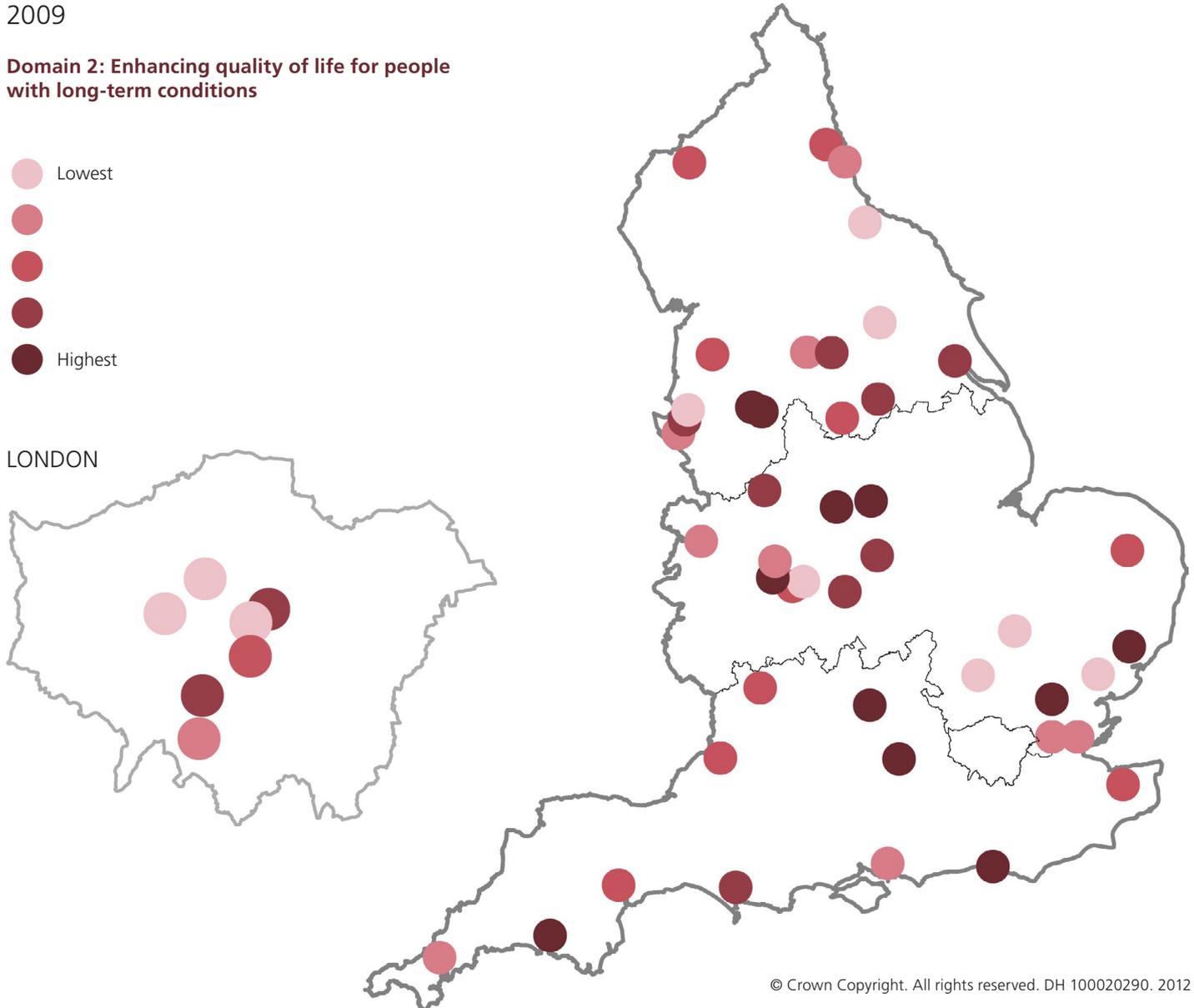
Map 10: Proportion (%) of prevalent dialysis patients receiving dialysis (haemodialysis and peritoneal dialysis) at home by renal centre

2009

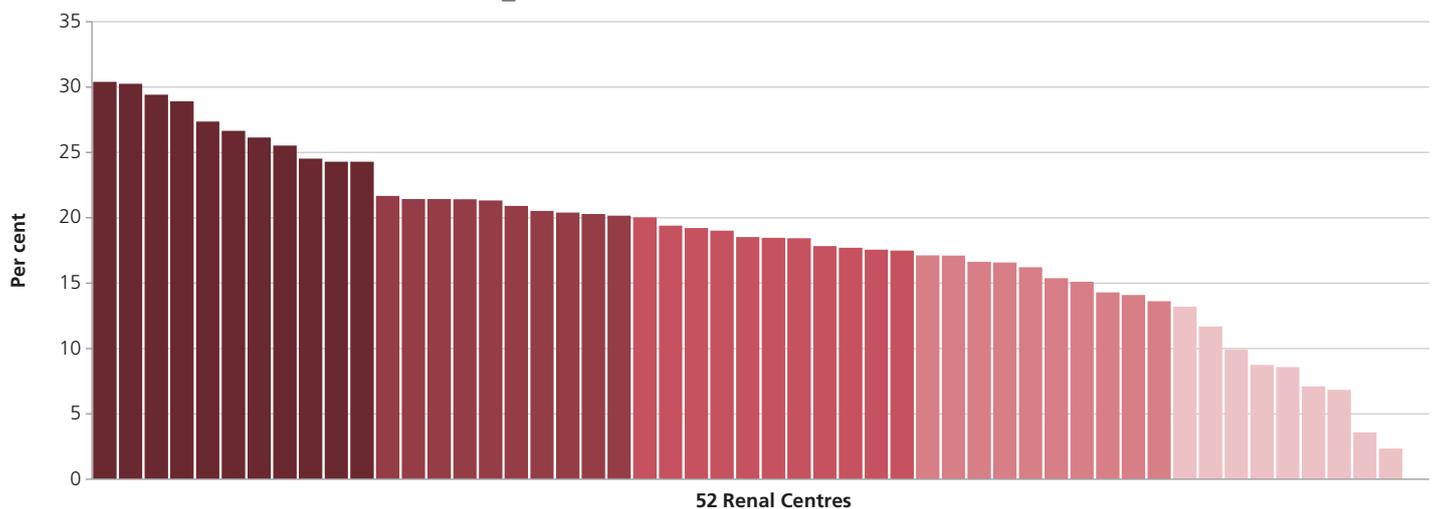
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

In 2009 in England, 53% of the 41,000 people on renal replacement therapy (RRT) were receiving one of two main types of dialysis, with the remaining 47% having a functioning kidney transplant. The two main types of dialysis are:

- › haemodialysis, in which blood is cleaned in an artificial kidney;
- › peritoneal dialysis, in which fluid is instilled into the patient's abdomen for a similar effect.

With adequate education, training and support, both treatments can be undertaken in a patient's home.

Patient choice was enshrined in the renal National Service Frameworks (see "Resources"). The results of studies have suggested that when dialysis patients are appropriately educated and informed one-third will choose a home-dialysis option. Although there are set-up costs for home haemodialysis, home therapies are generally less expensive than in-centre options. Home therapies are at least as effective as in-centre options with often unmeasured benefits in terms of patient empowerment and reduced carbon emissions.

Magnitude of variation

Map 10: Sum of dialysis at home

For renal centres in England, the proportion of prevalent dialysis patients receiving dialysis (haemodialysis and peritoneal dialysis) at home ranged from 0.0% to 30.4%.

In 8 of the 52 centres, more than 25% of patients were on home dialysis; in seven centres, less than 10% of patients were on home dialysis.

Map 11: Haemodialysis at home (page 42)

For renal centres in England, the proportion of prevalent dialysis patients receiving haemodialysis at home ranged from 0.0% to 11.2%.

Map 12: Peritoneal dialysis at home (page 43)

For renal centres in England, the proportion of prevalent dialysis patients receiving peritoneal dialysis at home ranged from 0.0% to 27.5%.

The provision of home dialysis requires the establishment of an infrastructure to support patients and carers, which may be difficult and expensive for smaller centres to set up and maintain. These smaller centres may refer patients to other larger centres for home dialysis, especially home haemodialysis. Currently, such patients are attributed to their current treatment centre (rather than their referring centre), potentially giving a misleading impression of the level of access to home dialysis at some centres.

Barriers to undertaking dialysis at home in the UK include:

- › staffing levels and attitudes;
- › in-centre dialysis capacity;
- › reimbursement incentives;
- › patient education programmes;
- › the range of treatments offered;
- › ability to insert catheters rapidly for peritoneal dialysis;
- › training and support once on home dialysis.

The UK Renal Registry is exploring the extent to which each of these factors explains regional variation in home dialysis in the UK. Research is also underway in Sheffield:

- › to explore how patients choose their initial dialysis modality;
- › to design a tool that will support shared decision-making.

The UK Renal Registry has established population catchment areas using Geographical Information Systems (GIS) which will enable the credit for home-dialysis patients to be given to referring renal centres. However, it is unlikely that this will explain all of the variation observed.

Options for action

Commissioners and providers need to investigate the cost-effectiveness of new models of providing dialysis at home utilising new and existing technologies for the increasingly frail elderly population, and to agree supportive funding arrangements.

Commissioners of dialysis services need to be aware of the health and financial benefits of treatment at home in order to plan and design services that are appropriate to the needs of the local population.

See also page 61, Case-study 3.

RESOURCES

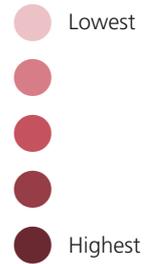
- › Department of Health (2004) National Service Framework for Renal Services: Part One – Dialysis and transplantation. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4070359
- › NICE (2002) Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure (Technology Assessment, TA48). <http://publications.nice.org.uk/guidance-on-home-compared-with-hospital-haemodialysis-for-patients-with-end-stage-renal-failure-ta48>
- › NICE Guidance (2011) Peritoneal dialysis: Peritoneal dialysis in the treatment of stage 5 chronic kidney disease (Clinical Guidelines, CG125). <http://www.nice.org.uk/guidance/CG125>
- › Castledine C, Gilg J, Rogers C et al (2010) In: The Renal Association UK Renal Registry, The Thirteenth Annual Report, December 2010. Chapter 15: RRT Incidence and use of Home Dialysis Modalities. http://www.renalreg.com/Report-Area/Report%202010/Chap15_Renal10_web.pdf

RENAL REPLACEMENT THERAPY

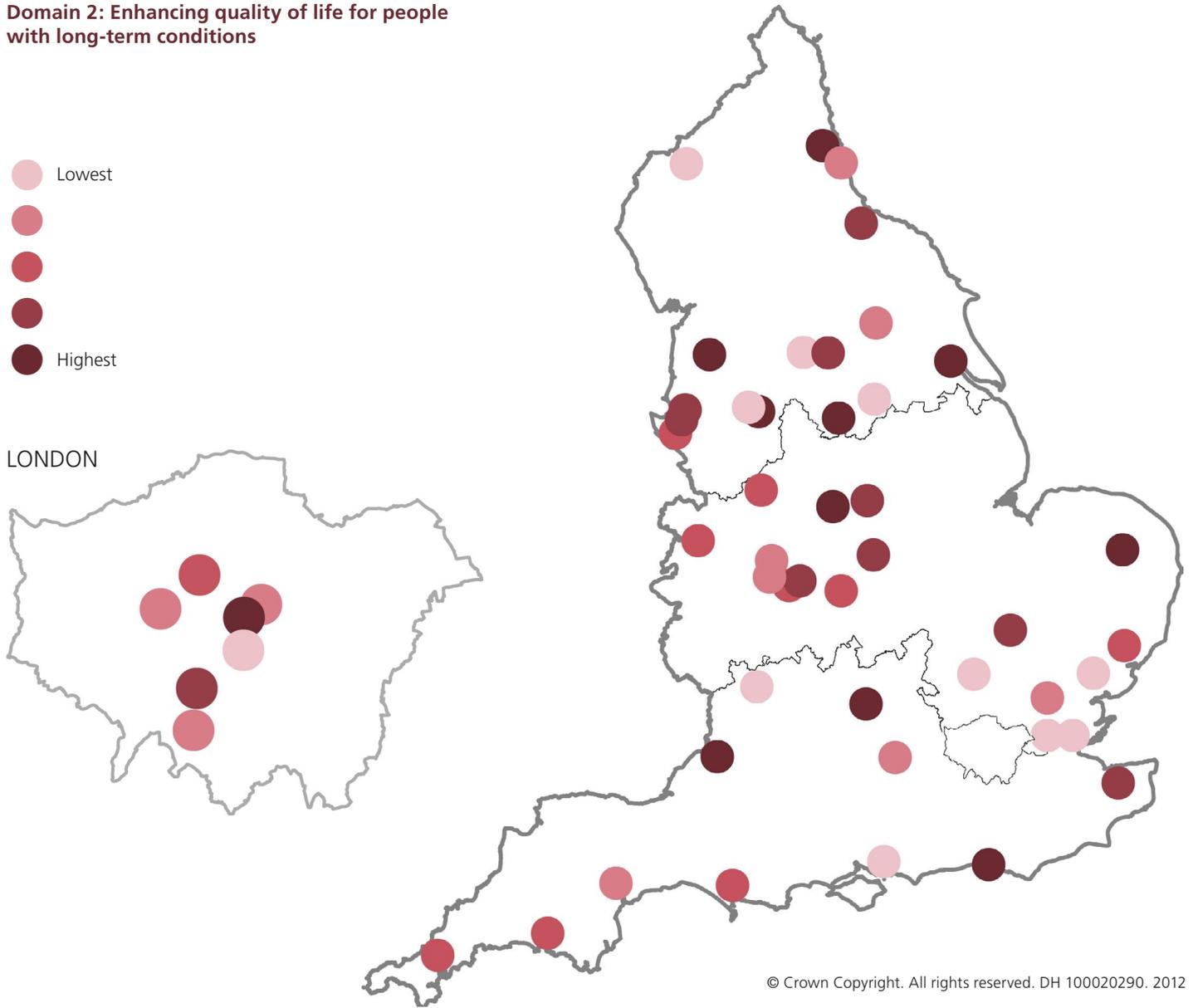
Map 11: Proportion (%) of prevalent dialysis patients receiving haemodialysis at home by renal centre

2009

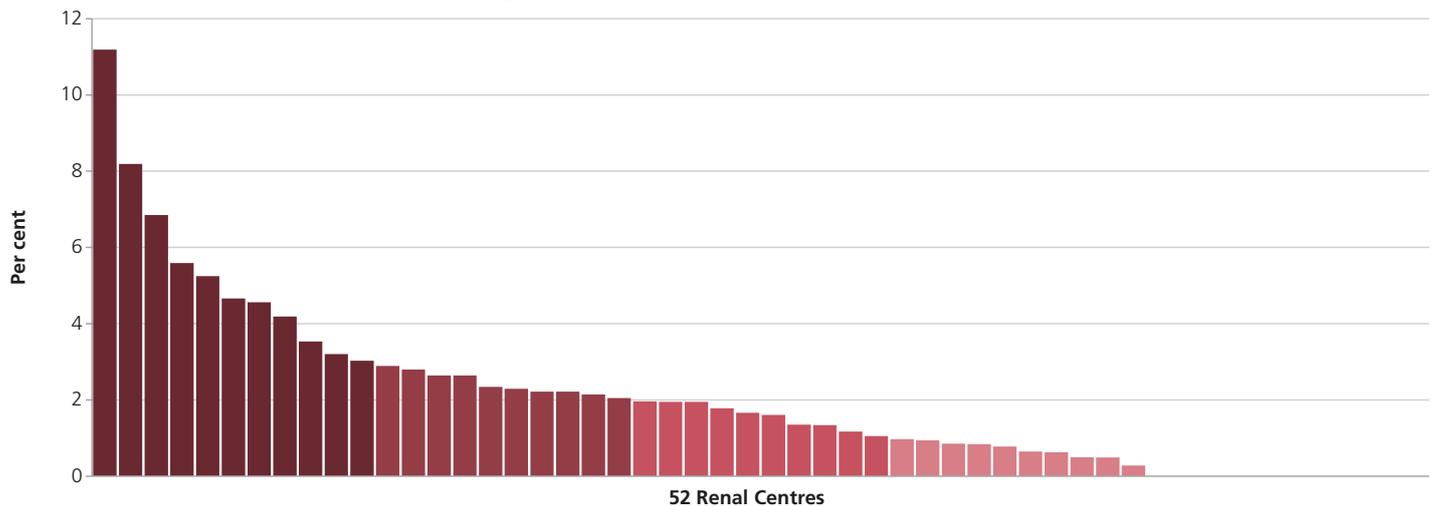
Domain 2: Enhancing quality of life for people with long-term conditions



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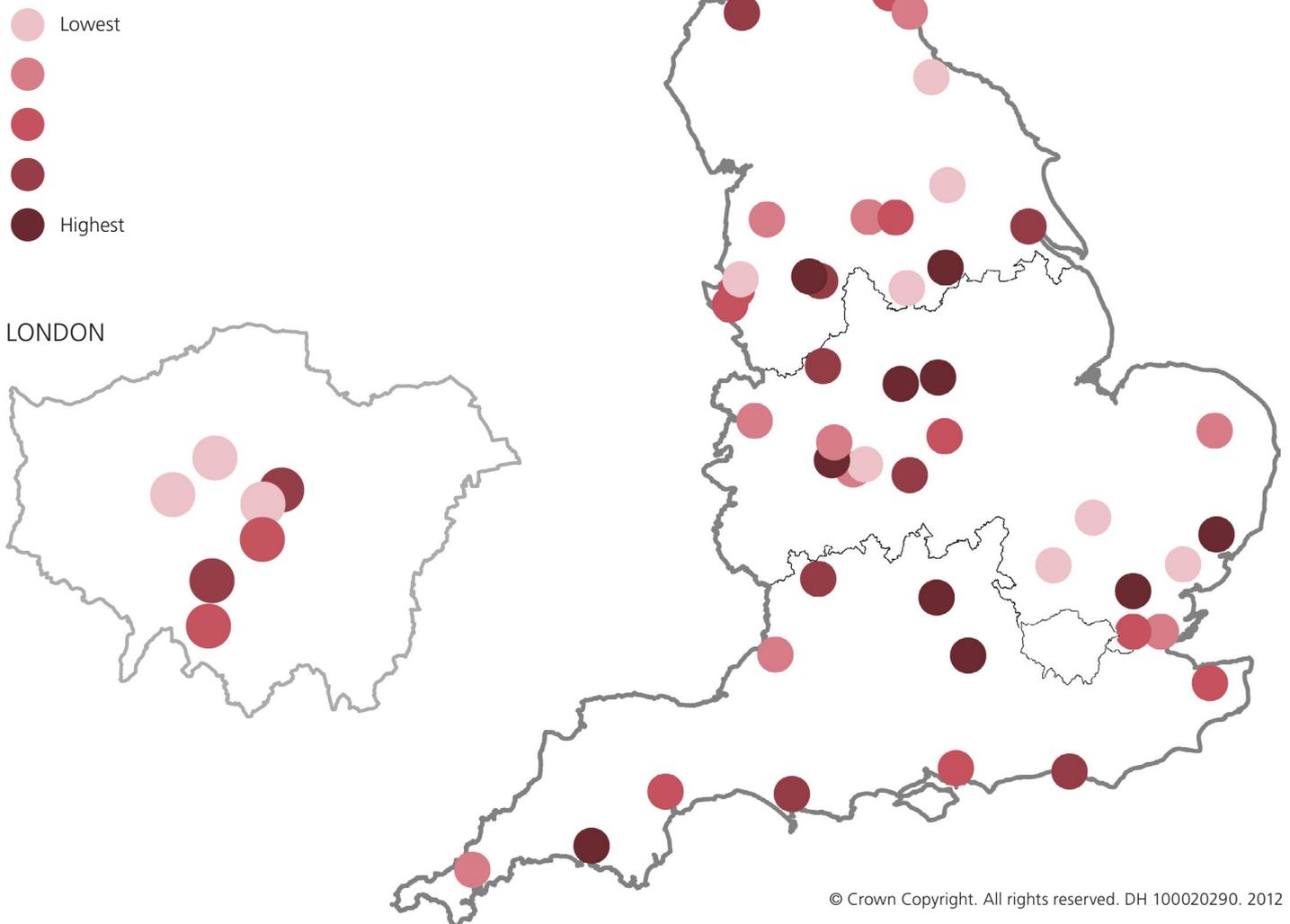


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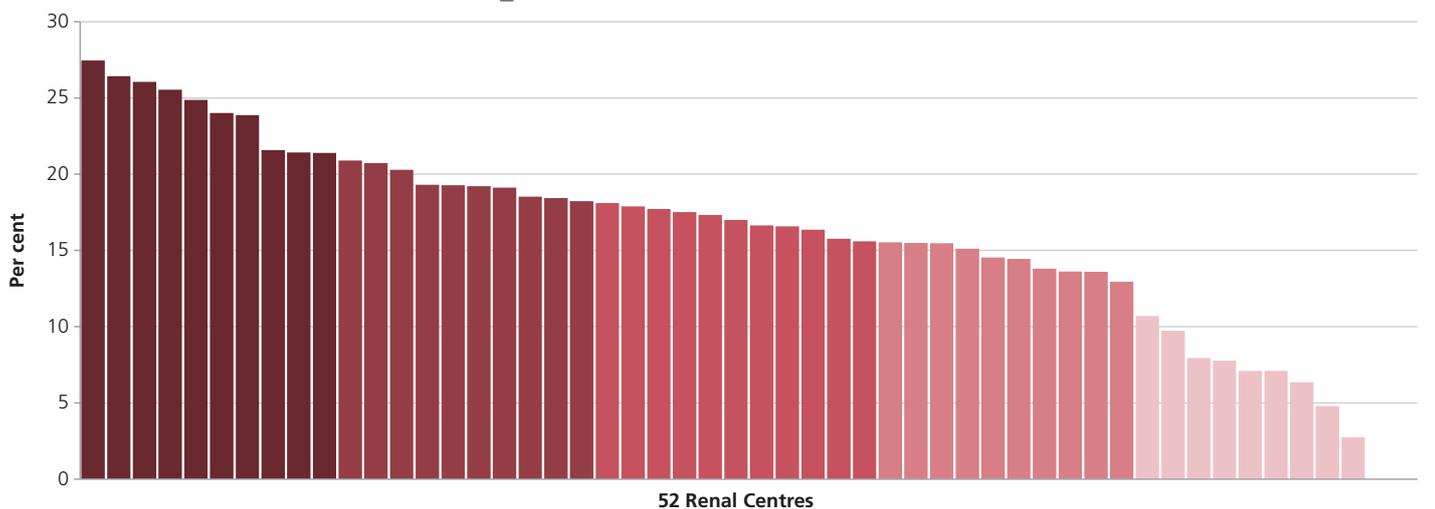
Map 12: Proportion (%) of prevalent dialysis patients receiving peritoneal dialysis at home by renal centre

2009

Domain 2: Enhancing quality of life for people with long-term conditions



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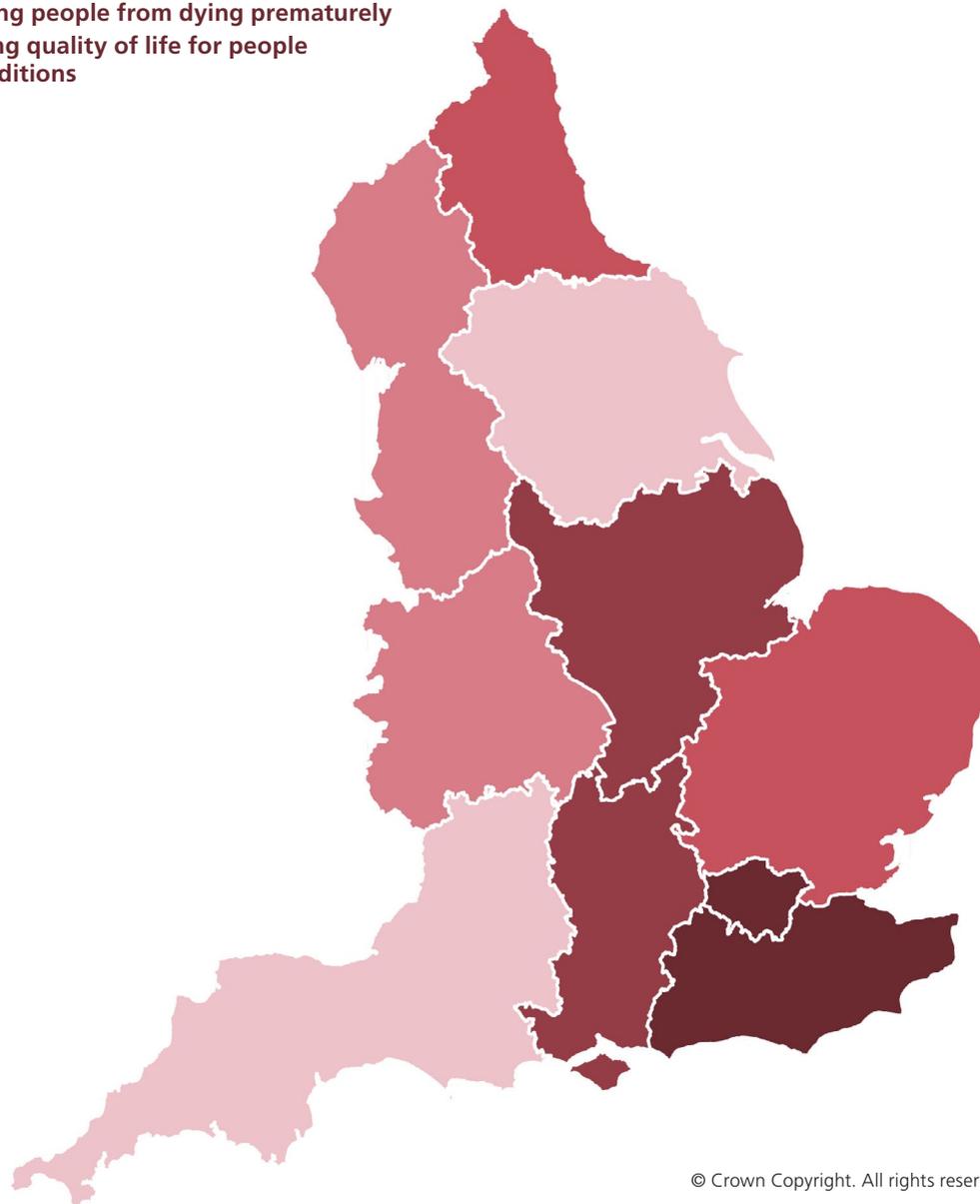


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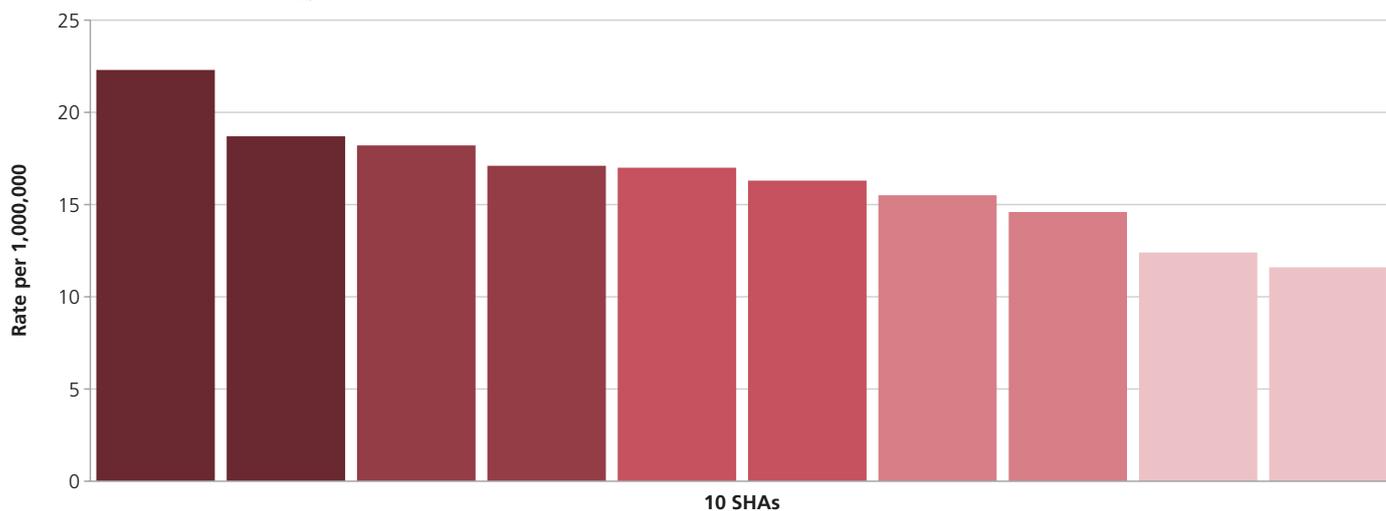
Map 13: Rate of kidney transplants from living donors per population by SHA

2010/11

Domain 1: Preventing people from dying prematurely
 Domain 2: Enhancing quality of life for people with long-term conditions



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Context

Living-donor kidney transplantation programmes have changed significantly in the last 10 years.¹ This has been influenced by changes in the legal framework,² new technologies and professional guidelines.^{3,4} Although there is no shortage of potential donor–recipient referrals, there is a high attrition rate from programmes due to recipient and donor complexities, including immunological and blood-group incompatibility and other co-morbidities. Planned living-donor kidney transplantation has become the treatment of choice for most complex recipients, accounting for much of the expansion in activity. Extending the criteria for acceptance of suitable donors in the context of emerging evidence, antibody depletion techniques and development of the National Living Donor Kidney Sharing Schemes has expanded the donor pool. The National Living Donor Kidney Sharing Schemes encompass both paired/pooled donation and altruistic non-directed donation.

The superior outcomes of living-donor kidney transplants and the opportunity to plan pre-emptive transplantation with its added benefits for patient and graft survival has motivated patients to seek this choice which has then driven service development. The avoidance of dialysis represents savings to the health economy.⁵

Donor safety is paramount to the success and sustainability of a national living-donor kidney transplant programme and all new developments must be underpinned by appropriate safeguards to protect the welfare of the donor.

Magnitude of variation

For strategic health authorities in England, the rate of kidney transplants from living donors ranged from 11.6 to 22.3 per million population (1.9-fold variation).

The rate of living donation in England is currently 16.5 per million population, which compares favourably with countries against which England has traditionally been benchmarked, such as Norway, which has a rate of 17 per million population. However, the degree of variation observed suggests that current rates of living donation fall short of the potential that could be achieved.

Reasons for variation in living donation are differences in:

- › population demographics, including ethnicity;
- › clinical practice;
- › logistical considerations, such as geographical distance to a transplanting centre;
- › commissioning arrangements.

Further investigation of these factors is required to understand the full impact on overall activity.

NHS Blood and Transplant (NHSBT) has identified that commissioning is key to sustaining living-donor activity. Robust organisational processes are required to underpin effective clinical pathways. However, not all living-donor kidney transplant programmes are equally mature, and there is variation in both capacity and capability. Mature programmes, offering the full range of living-donor options to their patients, are in the minority, and most programmes are in the process of development or re-development. Professionals responsible for all centres would like to expand the living-donation services they offer.

Options for action

In January 2012, NHSBT launched its UK Strategy for Living Donor Kidney Transplantation (see “Resources”) with the aim of promoting increases in living donation to match the best international benchmarks. Key themes in the strategy include:

- › an emphasis on donor safety;
- › pre-emptive transplantation;
- › further development of the National Living Donor Kidney Sharing Schemes.

The UK Strategy for Living Donor Kidney Transplantation is designed to support the aspirations of the clinical community and provides an opportunity to explore and address some of the barriers to living-donor kidney transplantation in order to increase the number of patients with chronic kidney disease who can benefit from transplantation.

See also page 63, Case-study 4.

RESOURCES

- › NHS Blood and Transplant (NHSBT) (2011) UK Strategy for Living Donor Kidney Transplantation 2010-2014, October 2011. http://www.organdonation.nhs.uk/ukt/how_to_become_a_donor/living_kidney_donation/questions_and_answers.asp
- › NHSBT. Information on transplant activity by centre and nationally. http://www.organdonation.nhs.uk/ukt/statistics/latest_statistics/latest_statistics.asp
- › NHSBT. Information on the process of allocation of living kidney donor organs. [http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/kidney_\(renal\)/living_donation/living_donation.jsp](http://www.organdonation.nhs.uk/ukt/about_transplants/organ_allocation/kidney_(renal)/living_donation/living_donation.jsp)
- › NHSBT Potential Donor Audit (PDA). http://www.organdonation.nhs.uk/ukt/statistics/potential_donor_audit/potential_donor_audit.asp

This indicator will be updated with 2011/2012 data in the Organ Donation and Transplantation Atlas. The Organ Donation and Transplantation Atlas also includes a map of the rate of kidney transplants from living donors per million population in 36 European countries.

1 NHS Blood and Transplant (2011) Transplant Activity in the UK, NHS Blood and Transplant Activity Report, 2010-2011. <http://www.nhsbt.nhs.uk>
 2 Human Tissue Act 2004. http://www.opsi.gov.uk/acts/acts2004/ukpga_20040030_en_1
 3 British Transplantation Society/Renal Association (2011) United Kingdom Guidelines for Living Donor Kidney Transplantation, 3rd version, May 2011. <http://www.bts.org.uk/>
 4 British Transplantation Society (2011) Guidelines for Antibody Incompatible Transplantation, January 2011. <http://www.bts.org.uk/>
 5 Specialised Commissioning Team, West Midlands (2010) Organs for Transplant: Cost Savings for the NHS, October 2010.

RENAL REPLACEMENT THERAPY

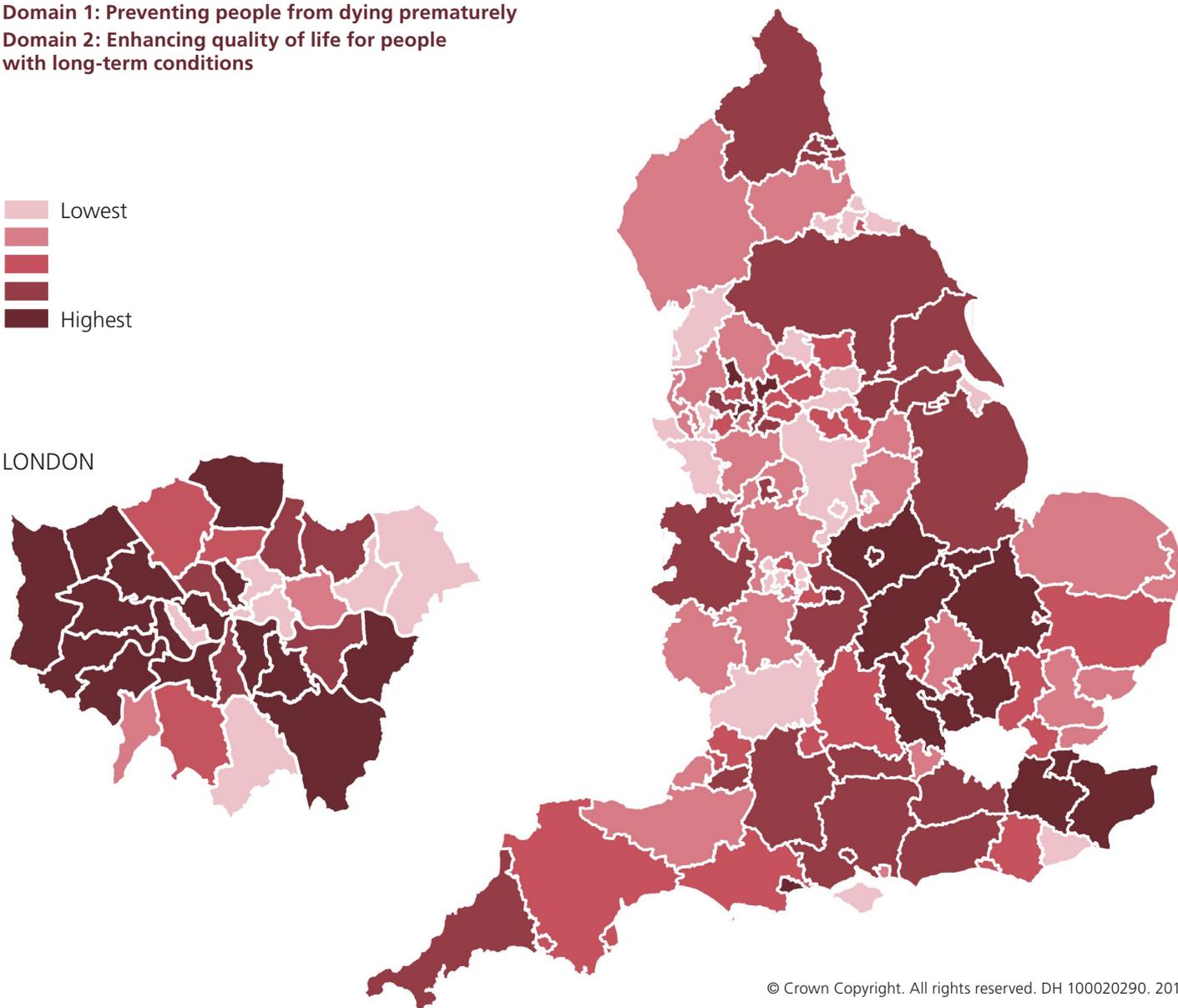
Map 14: Standardised pre-emptive transplantation ratio by PCT

Indirectly standardised ratio, adjusted for age and sex 2004–2009

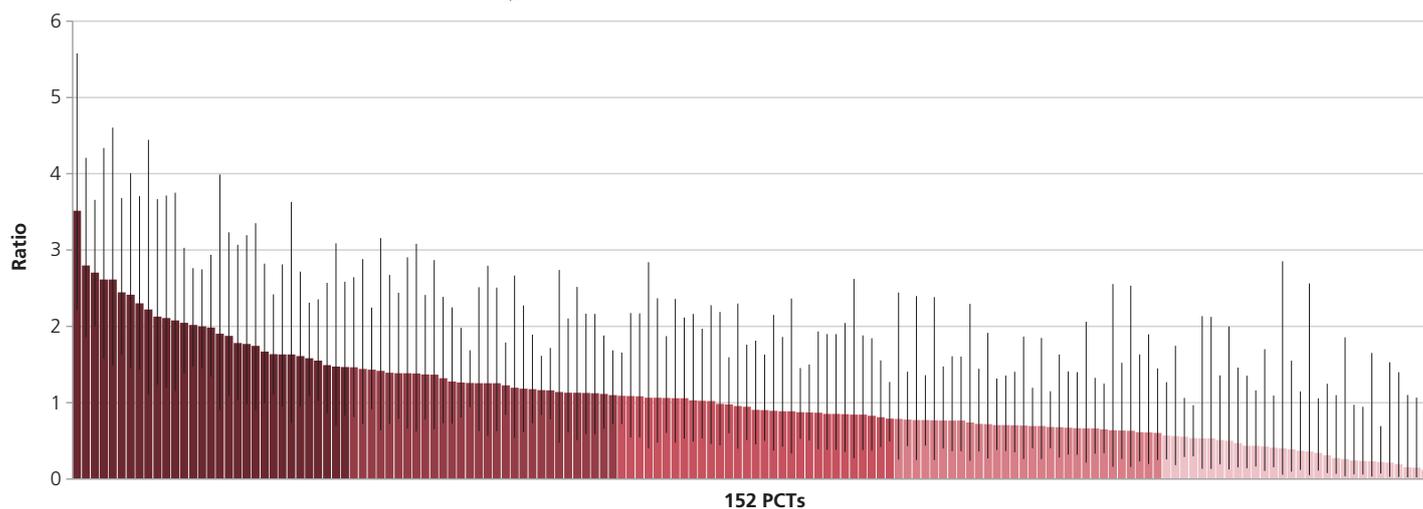
Domain 1: Preventing people from dying prematurely
Domain 2: Enhancing quality of life for people with long-term conditions



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Context

For suitable patients with end-stage renal disease (ESRD), when compared with remaining on dialysis, kidney transplantation confers benefits in terms of both survival and quality of life. Patients with ESRD may obtain a kidney transplant from either a deceased or living kidney donor. A pre-emptive transplant (i.e. a transplant before starting dialysis) is considered the 'gold standard' treatment option because not only does it maximise health outcomes for the patient but also it is the most cost-effective treatment option from a commissioner's perspective.

The current deceased-donor organ-allocation rules, in which priority is given to time on the waiting list, make it less likely that patients will receive a pre-emptive transplant through this route. Living-donor kidney transplantation, however, is an elective procedure and the timing can often be influenced by clinical care teams with appropriate patient engagement, thus enabling a better opportunity to achieve pre-emptive transplantation.

The data for this indicator were derived from UK Renal Registry records of incident ESRD patients in England between 2004 and 2009 for whom transplant was recorded as first RRT modality.

Magnitude of variation

For PCTs in England, the standardised pre-emptive transplantation ratio ranged from 0.1 to 3.5 (29-fold variation). When the five PCTs with the highest ratios and the five PCTs with the lowest ratios are excluded, the range is 0.2–2.4, and the variation is 11-fold.

For PCTs in England from 2004 to 2009, the rate of pre-emptive kidney transplantation ranged from 1 to 20 per million population per year.

Potential reasons for the degree of variation observed include differences in:

- Patient-dependent variables, such as demography, social deprivation, ethnicity, co-morbidity burden and attitudes towards kidney donation and transplantation;
- Patient-independent, resource-dependent variables, such as the number of live donor coordinators or transplant surgeons/nephrologists per unit population;
- Patient- and resource-independent variables, such as differences in the efficiency of patient pathways or clinical practice;
- The care provided by transplanting renal centres and non-transplanting renal centres.

Options for action

To improve local care and eliminate variability due to patient- and resource-independent factors, providers need:

- to review their patient pathways;
- to compare their performance on pre-emptive kidney transplantation with that of other renal centres, and identify the reasons why certain renal centres might have a better performance than their own.

Commissioners need to adopt an "invest to save" strategy to eliminate resource-dependent variability because pre-emptive transplantation is considerably more cost-effective than the other treatment options for ESRD.

RESOURCES

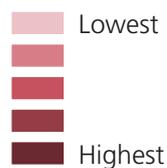
- Dudley C, Harden P (2011) Assessment of the Potential Kidney Transplant Recipient. Guideline 1.3 – Access to renal transplantation. Renal Association Clinical Guidelines. <http://www.renal.org/Clinical/GuidelinesSection/AssessmentforRenalTransplantation.aspx>

ACUTE KIDNEY INJURY

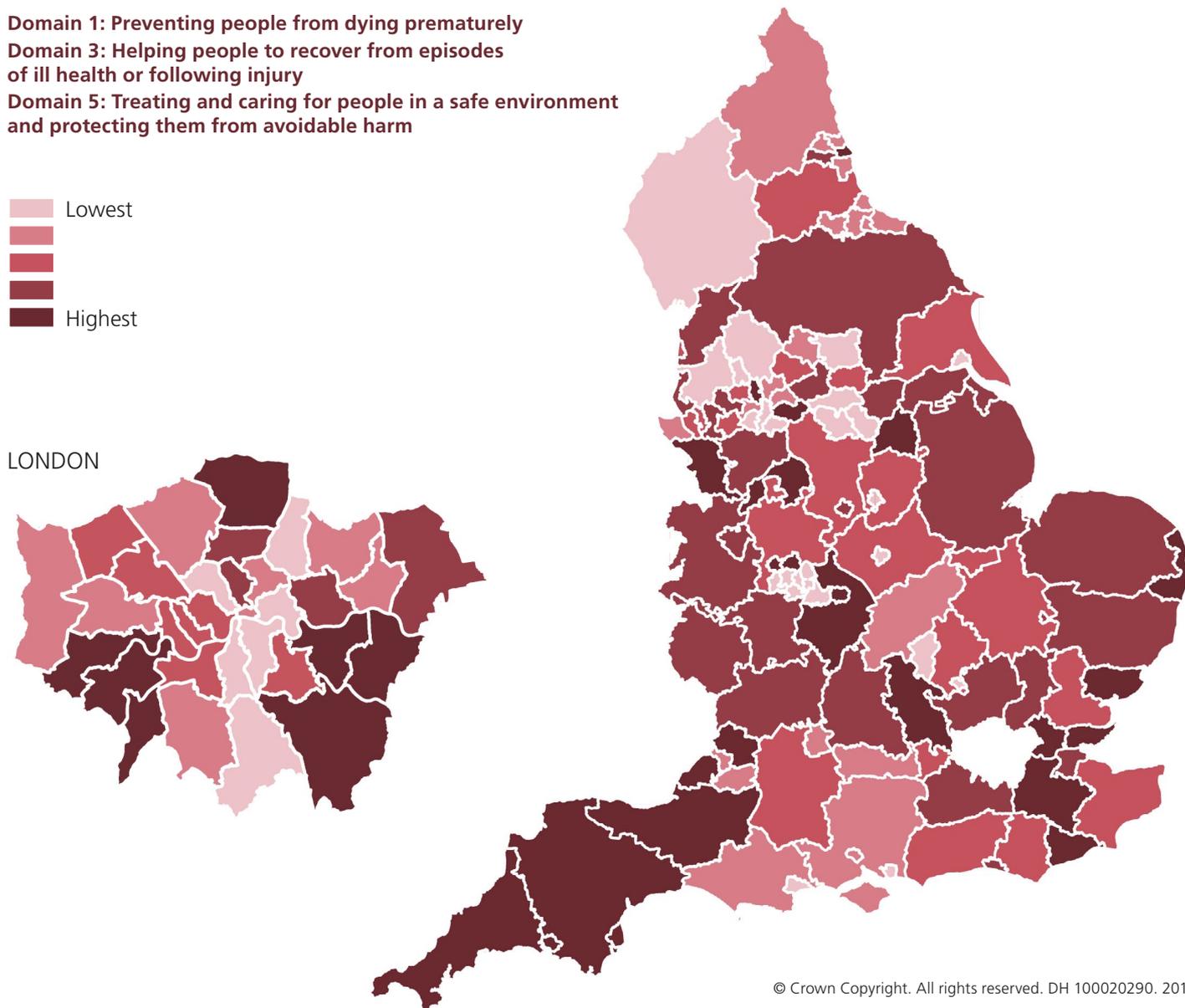
Map 15: Rate of admissions for acute kidney injury (AKI) per all emergency admissions to hospital by PCT

2010/11

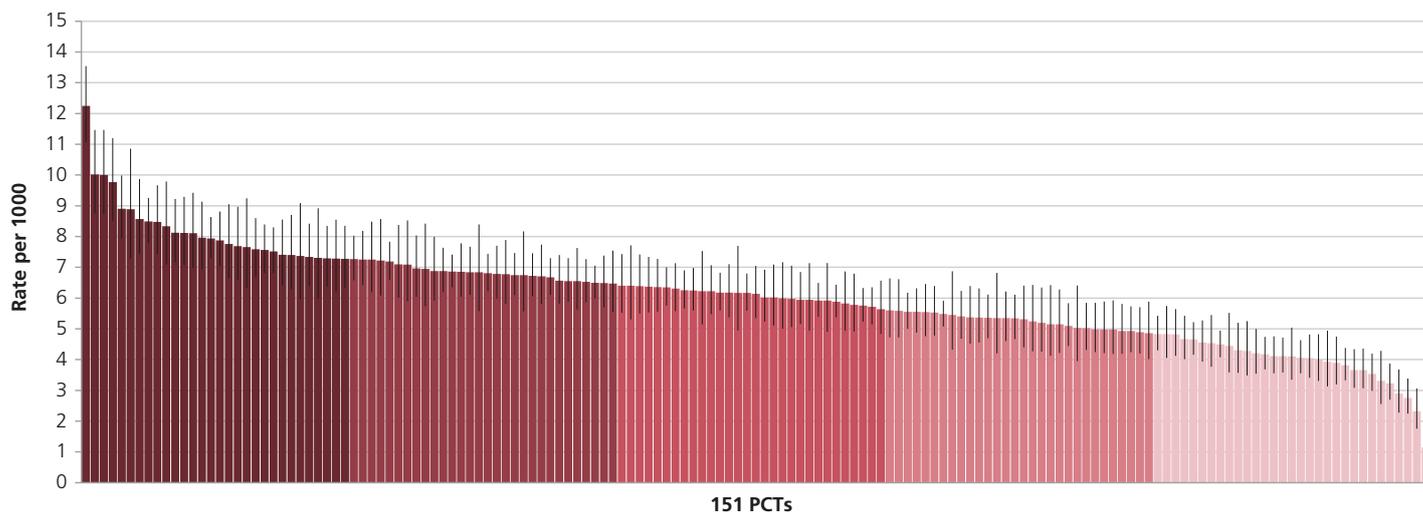
Domain 1: Preventing people from dying prematurely
 Domain 3: Helping people to recover from episodes of ill health or following injury
 Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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Context

Acute kidney injury (AKI), previously known as acute renal failure, is a medical emergency characterised by rapid loss of kidney function. It is very common, complicating up to 20% of hospital emergency admissions.¹ Older people and people with long-term conditions, such as chronic kidney disease or heart failure, are at greater risk of developing AKI.

Acute kidney injury is not usually the result of illness limited to the kidney. Severe infection, low blood pressure, medications and toxins may all contribute to AKI. Good management of acutely ill patients can prevent AKI in up to 30% of cases.² Early recognition and prompt treatment can limit the severity of AKI.

Acute kidney injury is associated with poor outcomes:

- › Up to 50% mortality in patients with severe AKI;³
- › Survivors may have permanent kidney damage or need lifelong renal replacement therapy.⁴

Management of AKI is resource intensive, costing the NHS £600 million per year, and associated with increases in length of stay.⁵ Admissions attributed to AKI have risen in recent years, possibly reflecting increasing awareness and clearer diagnostic criteria. However, the results of studies suggest growth in the prevalence of the condition.

Magnitude of variation

For PCTs in England, the rate of admissions for AKI per all emergency admissions ranged from 1.1 to 12.2 per 1000 emergency admissions to hospital (11-fold variation). When the five PCTs with the highest rates and the five PCTs with the lowest rates are excluded, the range is 3.3–8.9 per 1000 emergency admissions, and the variation is 2.7-fold.

In 2009/10, the rate was 0.4–9.4 per 1000 emergency admissions (25-fold variation), and when the five PCTs with the highest rates and the five PCTs with the lowest rates were excluded it was 3.4–8.2 per 1000 emergency admissions, a 2.4-fold variation [see Map 55, Atlas 2.0 (Amendments, August 2012)].

The degree of variation observed in 2010/11 could reflect differences in:

- › Distribution of risk factors for AKI;
- › Organisation and management of care of acutely unwell patients in local healthcare services;
- › Recognition of AKI by clinicians;
- › Accuracy and completeness of coding.

As many cases of AKI are not coded at present, current data probably represent only a fraction of the total burden of AKI on local populations and local health services.

Options for action

To reduce the degree of variation in AKI admissions, it is necessary to improve:

- › Awareness of AKI among all healthcare professionals;
- › Coding of admissions;
- › Quality of care of acutely unwell patients.

Commissioners need to consider:

- › Implementing an acute care CQUIN (see “Resources”);
- › Establishing defined AKI care pathways in every setting where acute illness is managed;
- › Including measures to improve AKI care in QIPP plans.

Clinicians can improve the care of the acutely unwell through:

- › Recognition of illness severity and physiological deterioration;
- › Prompt resuscitation;
- › Timely management of sepsis;
- › Safe and effective prescribing;
- › Monitoring and restoration of adequate fluid balance and nutrition;
- › Protocols for the referral and safe transfer of patients with AKI to specialist settings.

For managers, it is important:

- › To implement electronic AKI alerts in laboratory reporting systems;⁶
- › To audit AKI outcomes and quality of care;
- › To implement the recommendations of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) on AKI (see “Resources”).

See also page 65, Case-study 5.

RESOURCES

- › NHS Kidney Care. Acute Kidney Injury Resource Pack (includes audit tools, example protocols, guidelines and CQUIN schemes). http://www.kidneycare.nhs.uk/our_work_programmes/acute_kidney_injury/tools_to_help_you/
- › National Confidential Enquiry into Patient Outcome and Death (NCEPOD) (2009) *Acute Kidney Injury: Adding Insult to Injury*. <http://www.ncepod.org.uk/2009aki.htm>
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1 Uchino S, Bellomo R, Goldsmith D et al (2006) An assessment of the RIFLE criteria for acute renal failure. *Critical Care Medicine* 34; 1913–1917.

2 Stevens PE, Tamimi NA, Al Hasani MK et al (2001) Non-specialist management of acute renal failure. *Quarterly Journal of Medicine* 94; 533–540.

3 Waikar S, Liu K, Chertow G (2008) Diagnosis, Epidemiology and Outcomes of Acute Kidney injury. *Clin J Am Soc Nephrol* 3; 844–861.

4 Coca SG, Singanamala S, Parikh CR (2012) Chronic kidney disease after acute kidney injury: a systematic review and meta-analysis. *Kidney International* 81;442–448.

5 <http://www.hesonline.nhs.uk>

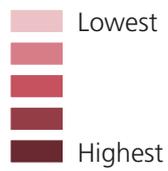
6 Garner AE, Lewington AJ, Barth JH (2012) Detection of patients with acute kidney injury by the clinical laboratory using rises in serum creatinine: comparison of proposed definitions and a laboratory delta check. *Ann Clin Biochem* Jan;49(Pt 1):59–62.

ACUTE KIDNEY INJURY

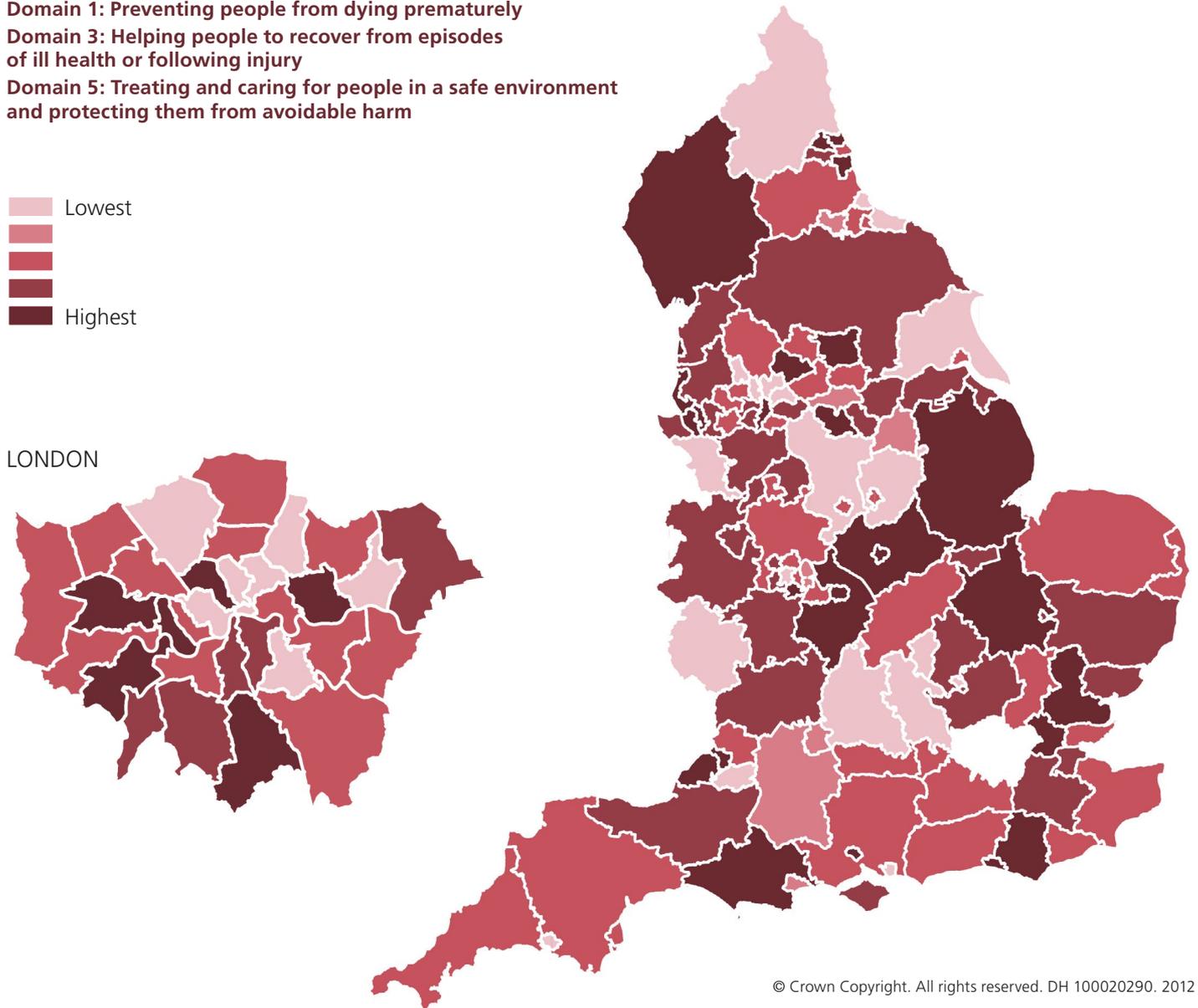
Map 16: Median length of stay (days) in admissions with a primary diagnosis of acute kidney injury (AKI) by PCT

2010/11

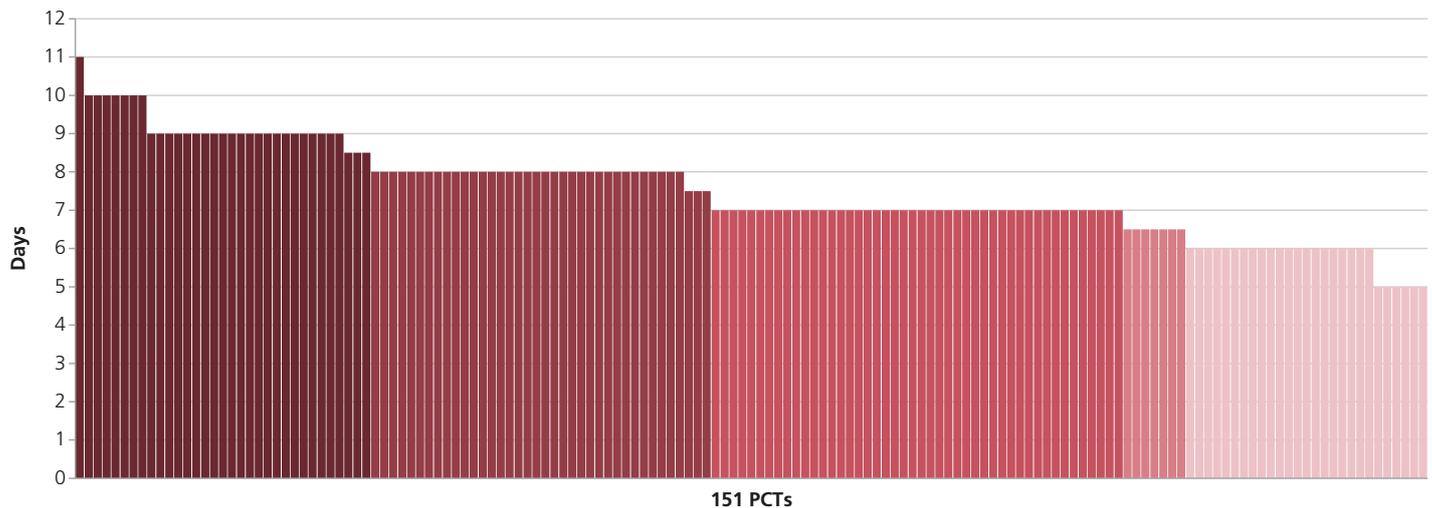
Domain 1: Preventing people from dying prematurely
 Domain 3: Helping people to recover from episodes of ill health or following injury
 Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm



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Context

Acute kidney injury (AKI), previously known as acute renal failure, is a medical emergency characterised by rapid loss of kidney function. It is very common, complicating up to 20% of hospital emergency admissions.¹ Older people and people with long-term conditions, such as chronic kidney disease or heart failure, are at greater risk of developing AKI.

Acute kidney injury is not usually the result of illness limited to the kidney. Severe infection, low blood pressure, medications and toxins may all contribute to AKI. Good management of acutely ill patients can prevent AKI in up to 30% of cases.² Early recognition and prompt treatment can limit the severity of AKI.

Acute kidney injury is associated with poor outcomes:

- Up to 50% mortality in patients with severe AKI;³
- Survivors may have permanent kidney damage or need lifelong renal replacement therapy.⁴

Management of AKI is resource intensive, costing the NHS £600 million per year, and is associated with increases in length of stay.⁵ The effect of AKI on length of stay increases with the severity of AKI and is magnified in AKI survivors.⁶ Different models of provision of specialist renal care in acute trusts in England are associated with variation in mortality rates and in length of stay.⁷

Magnitude of variation

For PCTs in England, the median length of stay in admissions with a primary diagnosis of AKI ranged from 5.0 to 11.0 days (2.2-fold variation). When the five PCTs with the longest mean lengths of stay and the five PCTs with the shortest mean lengths of stay are excluded, the range is 5.0–10.0 days, and the variation is 2-fold.

Coding may have a large influence on the degree of variation observed in median length of stay in patients with AKI in terms of:

- Accuracy and completeness of coding;
- Coding of cases of AKI that are less severe.

The degree of variation may also be influenced by differences in:

- Mortality rates in patients with AKI;
- Organisation and management of care of acutely unwell patients in local healthcare services;
- Recognition and early management of AKI by clinicians;
- Provision of treatment at specialist regional centres for the most severe cases of AKI.

Options for action

To reduce the variation in median length of stay for AKI, it is necessary to improve:

- Awareness of AKI among all healthcare professionals;
- The quality of care of acutely unwell patients.

Commissioners need to consider:

- Implementing an acute care CQUIN (see “Resources”);
- Establishing defined AKI care pathways in every setting where acute illness is managed;
- Including measures to improve AKI care in QIPP plans.

Clinicians can improve care of the acutely unwell through:

- Recognition of illness severity and physiological deterioration;
- Prompt resuscitation;
- Timely management of sepsis;
- Safe and effective prescribing;
- Monitoring and restoration of adequate fluid balance and nutrition;
- Protocols for the referral and safe transfer of patients with AKI to specialist settings.

For managers, it is important:

- To implement electronic AKI alerts in laboratory reporting systems;⁸
- To audit AKI outcomes and quality of care;
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See also page 65, Case-study 5.

RESOURCES

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- National Confidential Enquiry into Patient Outcome and Death (NCEPOD) (2009) *Acute Kidney Injury: Adding Insult to Injury*. <http://www.ncepod.org.uk/2009aki.htm>
- Lewington A, Kanagasundaraman S (2011) Acute Kidney Injury. Renal Association Clinical Guidelines. <http://www.renal.org/Clinical/GuidelinesSection/AcuteKidneyInjury.aspx>
- NICE Guidance (2007) Acutely ill patients in hospital (Clinical Guidelines, CG50). <http://www.nice.org.uk/CG50>

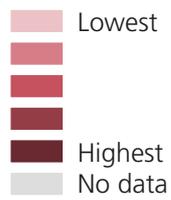
- 1 Uchino S, Bellomo R, Goldsmith D et al (2006) An assessment of the RIFLE criteria for acute renal failure. *Critical Care Medicine* 34; 1913–1917.
- 2 Stevens PE, Tamimi NA, Al Hasani MK et al (2001) Non-specialist management of acute renal failure. *Quarterly Journal of Medicine* 94; 533–540.
- 3 Waikar S, Liu K, Chertow G (2008) Diagnosis, Epidemiology and Outcomes of Acute Kidney injury. *Clin J Am Soc Nephrol* 3: 844–861.
- 4 Coca SG, Singanamala S, Parikh CR (2012) Chronic kidney disease after acute kidney injury: a systematic review and meta-analysis. *Kidney International* 81;442-448.
- 5 <http://www.hesonline.nhs.uk/>
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PATIENT EXPERIENCE

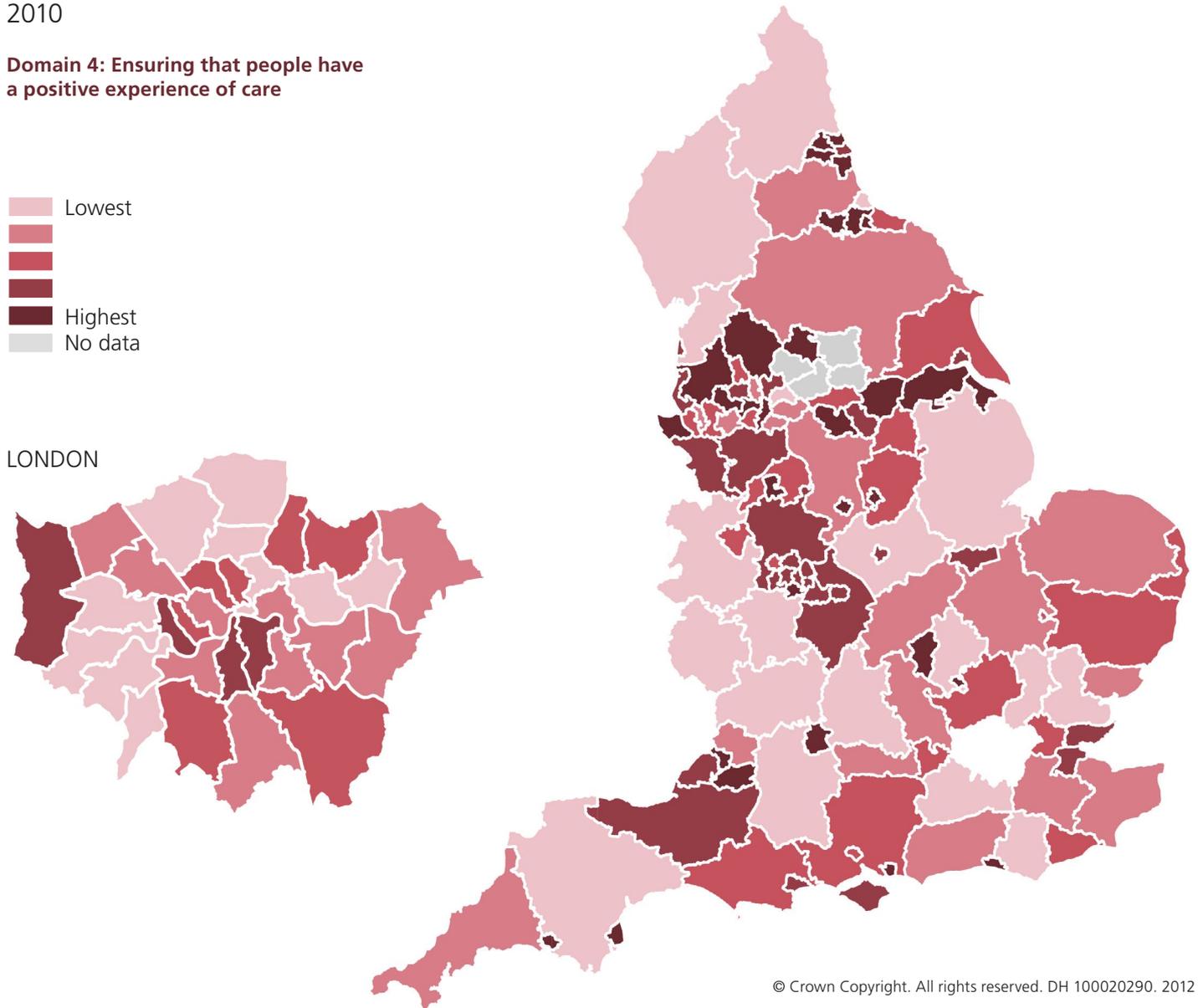
Map 17: Percentage of respondents in the haemodialysis travel survey with a journey time of 30 minutes or less by PCT

2010

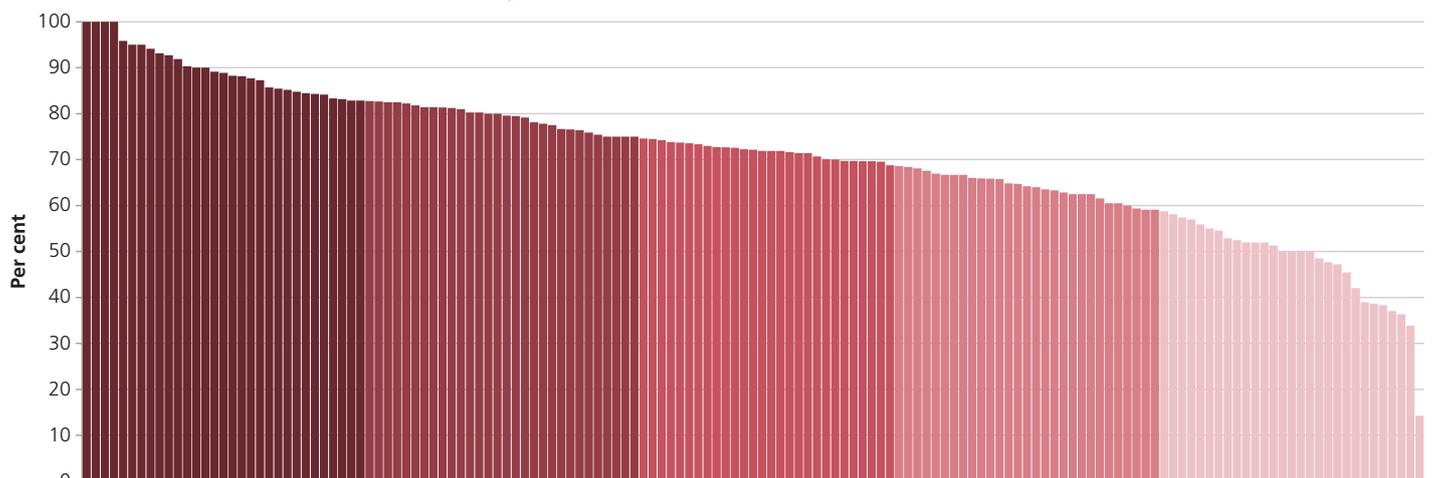
Domain 4: Ensuring that people have a positive experience of care



LONDON



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147 of 151 PCTs (missing data for 4 PCTs)

Context

Renal replacement therapy (RRT) is a lifelong treatment for patients with end-stage renal disease. Renal replacement therapy takes the form of either kidney transplantation or dialysis treatment. Dialysis can be divided into two broad modalities:

1. peritoneal dialysis, a home-based therapy, usually administered by a patient with or without a carer;
2. haemodialysis, which can also be performed at home, but the majority of approximately 18,000 haemodialysis patients in England have their haemodialysis in a dialysis unit.

Most of the haemodialysis patients attending dialysis units receive dialysis on three days per week, with approximately four hours' treatment during each session. Given the frequency and the lifelong need for treatment, it is not surprising that patients find it difficult to cope with long journeys to and from dialysis. In addition to concerns about patient experience, there is evidence that travel time to dialysis is a predictor of adherence to and the complications of treatment.

In the Patient Transport Survey 2010, all unit-based haemodialysis patients were asked to estimate the amount of time their journey had taken that day. The response rate was 67%.

When journey time was analysed, 68% of all respondents had a journey time to the dialysis unit of 30 minutes or less; in 2008, 65% of respondents had had a journey time of 30 minutes or less.

It was also found that of the unit-based haemodialysis patients who responded:

- 31% travelled by private transport;
- 5% travelled by public transport;
- 64% relied on patient-transport services.

Magnitude of variation

For PCTs in England, the percentage of respondents in the haemodialysis travel survey with a journey time of 30 minutes or less ranged from 14.3% to 100% (7-fold variation).¹ When the five PCTs with the highest percentages of respondents with journey times of 30 minutes or less and the five PCTs with the lowest

percentages of respondents with journey times of 30 minutes or less are excluded, the range is 38.7–95.0%, and the variation is 2.5-fold.

In general, journey times were found to be longer in:

- PCTs in rural areas, reflecting the longer distances patients may need to travel;
- PCTs in urban conurbations, highlighting the difficulties of travelling on congested roads in large cities.

However, within these overall patterns, journey times were also found to depend on:

- The proximity of the patient's home to the dialysis unit;
- The quality of road and/or public transport links to the dialysis unit;
- The efficiency of the patient-transport provider.

Options for action

When planning dialysis services, commissioners need to be fully aware of the importance patients place on the journey time to the dialysis unit. To reduce or even avoid long journey times for haemodialysis patients, commissioners need to consider:

- Facilitating an increase in the number of patients who can use home-based therapies, including home haemodialysis treatment;
- Planning new dialysis units at locations near to where patients live, and which have good transport links and access to parking;
- Making journey time a key metric in measuring the quality of the service for patients who rely on the NHS for transport due to medical reasons.

RESOURCES

- NHS Information Centre (2011) National Kidney Care Audit. Patient Transport Survey 2010.
http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NHS_Patient_Transport_2010_Final_Web_Version_1.pdf
- Department of Health (2004) The National Service Framework for Renal Services. Part 1: Dialysis and Transplantation.
http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4137331.pdf

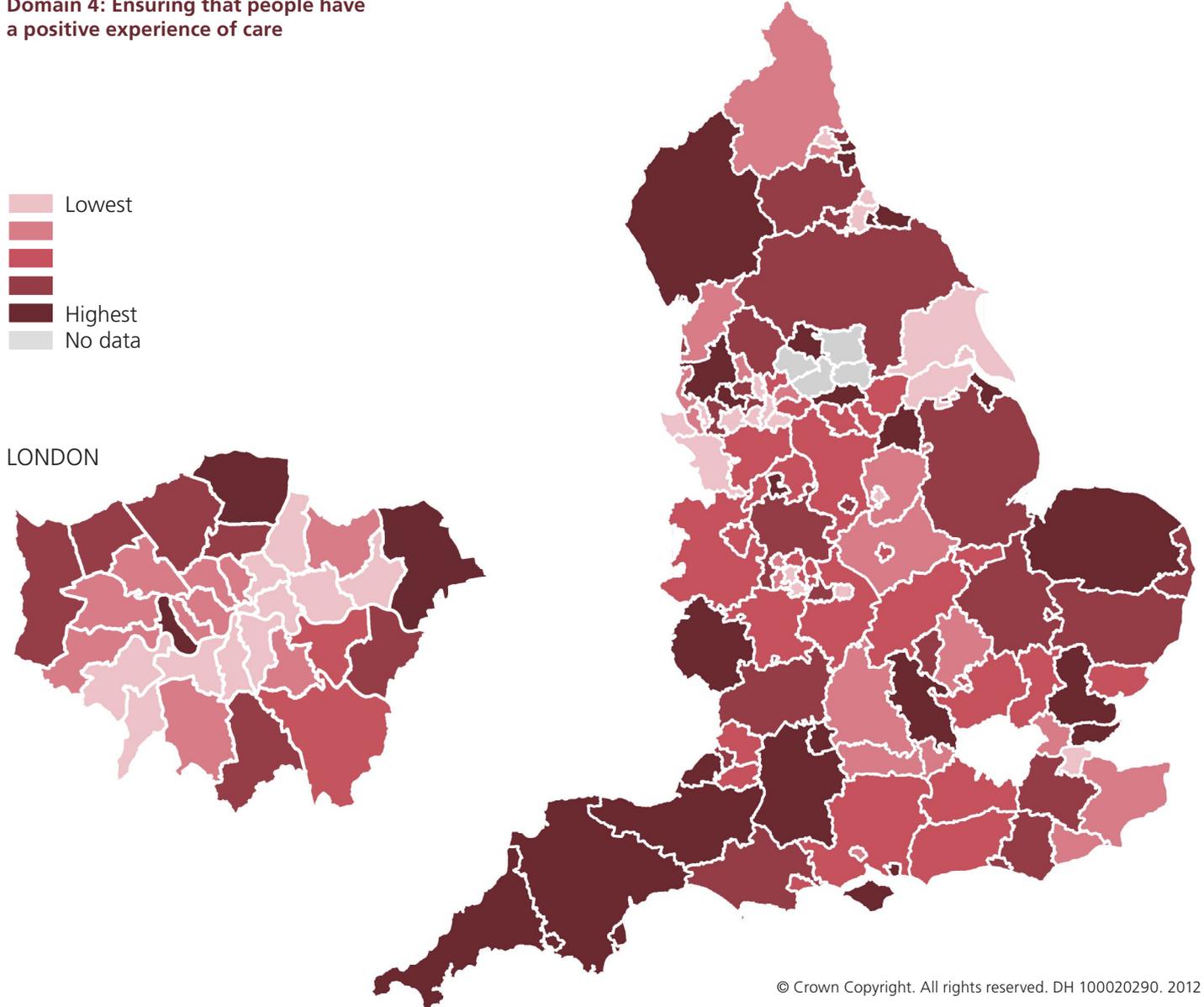
¹ Data from 4 PCTs are missing.

PATIENT EXPERIENCE

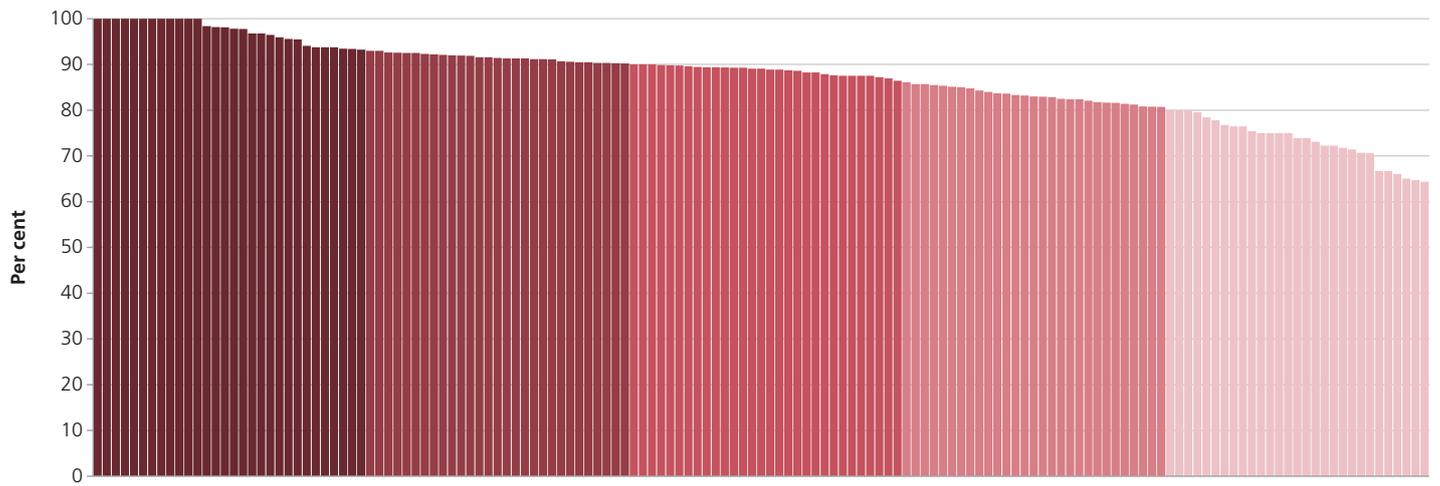
Map 18: Percentage of respondents in the haemodialysis travel survey satisfied with their transport service by PCT 2010

2010

Domain 4: Ensuring that people have a positive experience of care



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147 of 151 PCTs (missing data for 4 PCTs)

Context

Patient-reported outcome measures (PROMs) are a powerful means of assessing the quality of care as perceived by the patient. Sixty-five per cent of patients who have haemodialysis at a main renal centre or a satellite unit use hospital-provided transport to travel to and from dialysis sessions. As haemodialysis is normally performed three times a week, this can represent a considerable investment of time on the part of the patient.

Difficulties with transport can affect patient experience negatively and have been found to be associated with poor adherence to treatment and poor outcomes. Coping with dialysis can be hard; additional problems due to transport may cause unnecessary and avoidable stress and upset for patients.

Two National Kidney Care Audit Patient Transport Surveys have been undertaken to collect the views of patients from across the country. Recommendations to improve transport have been made on the basis of the findings from these surveys.

The data for this indicator have been drawn from the 2010 survey. Patients were asked to state whether their transport service met their personal needs either all or most of the time.

Magnitude of variation

For PCTs in England, the percentage of respondents in the haemodialysis travel survey satisfied with their transport service ranged from 64.4% to 100.0% (1.6-fold variation).¹ When the five PCTs with the highest percentages of respondents satisfied with their transport service and the five PCTs with the lowest percentages of respondents satisfied with their transport service are excluded, the range is 66.7–100.0%, and the variation is 1.5-fold.

The degree of variation observed in patient experience with their transport service to and from dialysis is considerable. In some PCTs, all patients were happy with the transport service, whereas in other PCTs one in three patients did not feel that the transport service met their personal needs.

Patient experience is not only influenced by travel time to and from dialysis: some of the localities in which patient experience is not as good can be localities with quicker travel times. Responses to the patient transport surveys highlight other factors important to patient experience, including:

- the attitude of and care demonstrated by drivers;
- the number of stops made during the journey.

Options for action

To improve patient experience of transport services to and from the dialysis unit, it is important to involve patients in commissioning those services.

Providers of dialysis services need:

- To ensure that there is adequate planning of transport services to reduce unnecessary delays;
- To monitor and audit transport performance regularly;
- To ensure that accountability and complaint mechanisms are transparent and easily accessible;
- To assess patient perceptions of transport services regularly as part of a wider initiative to assess patients' quality of life and experience of care.

For patients able to take their own transport to the dialysis unit, commissioners and relevant service providers need to consider appropriate means through which these patients can claim travel expenses.

RESOURCES

- NHS Information Centre (2011) National Kidney Care Audit. Patient Transport Survey 2010.
http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/NHS_Patient_Transport_2010_Final_Web_Version_1.pdf
- NHS Kidney Care. National Kidney care Audit – Patient Transport Survey Report: ability to view report by Strategic Commissioning Group (SCG).
http://www.kidneycare.nhs.uk/_Resources-Reports-PatientTransportSurveyReport.aspx

¹ Data from 4 PCTs are missing.

Case-study 1: Community-based service for chronic kidney disease patients

Setting

General practice in South Birmingham.

The situation or problem

General practitioners (GPs) in South Birmingham found that a large number of their patients with moderate chronic kidney disease (CKD) were visiting hospital once or twice a year to have their condition monitored and managed. The GPs believed it would be appropriate to manage these patients in primary as opposed to secondary care, not only to increase convenience for patients but also to improve efficiency in local health services.

In addition, the GPs were aware of a considerable gap between expected and actual prevalence of CKD stages 3–5 in their area. Although the expected prevalence in South Birmingham is 8%, the recorded prevalence was around 5% and ranged from 1% to 12% among different practices. This raised the question whether there could also be variation in the care provided.

What action was taken?

General practitioner, Dr Rajib Pal, was the vascular lead for South Birmingham Primary Care Trust (PCT)¹ until September 2011. Working with clinical and managerial colleagues from primary and secondary care, he set up and chaired the South Birmingham renal steering group which included patient representatives.

The steering group developed plans for a community-based service to manage patients with CKD stage 3b. There are around 1000 known patients with this level of CKD in South Birmingham: they are largely stable and mostly require monitoring and management to prevent deterioration. The steering group thought that these patients could be managed more appropriately in the community when compared with secondary care.

To ensure that the new community-based service not only delivered the same quality of care as secondary care

provider services but also improved upon them, three quality standards were developed (see Box CS1.1).

Box CS1.1: Quality standards developed for the community-based service for patients with CKD3b in South Birmingham

- Twice-yearly full blood tests
- Cardiovascular risk assessments for all patients aged between 40 and 74 years who are not already on a cardiovascular register
- An enhanced blood-pressure target of 130/80 mmHg

As blood pressure is one of the main risk factors for deterioration in CKD, the decision was made to try to achieve a lower blood-pressure target than that of 140/85 mmHg set as a standard in the Quality and Outcomes Framework (QOF) for primary care.

The community-based service for patients with CKD3b was introduced by the PCT as a Locally Enhanced Service (LES), according to which practices receive an extra payment for delivering the service. Patients with CKD3b who have complications or need regular specialist input continue to be seen in secondary care or are referred back to primary care in line with NICE CKD guidelines.

What happened as a result?

Of the GP practices in the PCT, 90% signed up for the scheme.

Although it is too early to show evidence of quantifiable benefits, the anticipated benefits of the scheme include:

- better health outcomes for patients, with reduced progression to CKD stages 4 and 5 and reduced cardiovascular mortality;
- increased awareness and understanding of kidney disease in primary care;
- increases in levels of reported prevalence;

¹ NHS South Birmingham is now part of the Birmingham and Solihull NHS cluster.

- an increase in appropriate referrals to secondary care and a decrease in inappropriate referrals;
- improved quality, efficiency and convenience of service for patients;
- holistic and integrated care for patients, with their GPs able to offer a single package of care for multiple conditions.

Using the QKidney® risk calculator,² the steering group estimated that South Birmingham PCT could save £80,000 over five years by lowering blood pressure in patients with CKD3b from 140/85 mmHg to 130/80 mmHg, thereby preventing strokes and heart attacks and the progression of CKD.

Learning points

Any shift of services requires primary and secondary care clinicians and managers to work together. The formation of the steering group was seen as pivotal in driving the

plans forward. Using the latest NICE guidance³ as the foundation for the scheme ensured that clinicians and managers were working from an agreed evidence base.

To obtain approval for the scheme, it was necessary to develop a clear and compelling business case to present to commissioners, in which was brought together evidence and guidelines on best practice, the proposed quality standards and the financial implications.

Key resources required for implementation

The key resource for the development and implementation of the scheme was time, and in particular the time of the steering group members:

- to develop the service specification and the business case;
- to promote the service and its benefits to GP practices.

2 The QKidney® risk calculator was developed by Julia Hippisley-Cox and Carol Coupland and based on routinely available data from GPs in the UK who freely contributed to the QResearch database for medical research. <http://www.qkidney.org/>

3 NICE Guidance (2008) Early identification and management of chronic kidney disease in adults in primary and secondary care (Clinical Guidelines, CG73). <http://www.nice.org.uk/CG73>

Case-study 2: Dedicated clinic to improve urgent dialysis care

Setting

Barts and The London Renal Centre is one of the largest centres for patients with kidney disease in England and is based at the Royal London in Whitechapel, East London.

The situation or problem

Patients with advanced kidney disease require renal replacement therapy (RRT): peritoneal dialysis, haemodialysis or a kidney transplant. Patients with chronic kidney disease whose kidney function is deteriorating are usually referred from a general nephrology clinic to a 'low clearance' or pre-dialysis clinic at which the focus is to slow the progression of the disease and prepare patients medically and psychologically for their chosen RRT modality.

The low clearance clinic plays an important role in preparing patients. Patients' blood levels are optimised, and they are educated about the treatment options available to them and the ways of managing their diet and fluid intake. This preparation allows patients, their families and carers the time to come to terms with their condition, and the impact the treatment will have on their daily lives; it also gives them time to adjust to their new diet and fluid intake regime.

Pre-dialysis patients are able to consider their preferred modality of RRT and can weigh up the advantages and disadvantages of the different modalities and whether they want to be listed for a transplant.

Once patients have decided on their preferred RRT, they can begin preparation and appropriate training. For patients choosing haemodialysis, they can also have a fistula established in their arm well in advance. For patients wishing to undergo peritoneal dialysis, a catheter is inserted into the abdomen, and training is arranged.

Sometimes, patients need RRT at short notice, and there is no time to prepare. This can happen for several reasons:

- A patient may have had stable kidney disease in a general nephrology clinic but then had an illness that affected their residual kidney function;

- A patient may have been known to the kidney service but missed appointments and presented with deterioration of their kidney function to the stage of requiring RRT;
- A patient may have been completely unaware that they had kidney disease but their condition had suddenly worsened – this can be common in people with diabetes or undiagnosed high blood pressure.

Clinicians at the Barts and the London Renal Centre found that patients were frequently 'crash landing' and in need of urgent inpatient haemodialysis. In part, this is due to the demographic of the local population, in which there is a large Asian community, known to have a higher prevalence of diabetes and high blood pressure, and who tend not to visit the GP until symptoms are advanced.

Patients who present late for dialysis are unable to go through the period of preparation described above. As a result, dialysis leaves them feeling lethargic and very unwell and they need to dialyse through a temporary line rather than a fistula for some time. These patients and their families and carers struggle to adapt to the sudden but necessary changes in lifestyle, diet and fluid intake.

Late presentation for dialysis is very costly for the health service because patients need to be admitted as emergency inpatients with considerable lengths of stay. Ultimately, evidence shows that patients who present late for dialysis have worse health outcomes and a higher level of morbidity.

What action was taken?

In June 2009, Breeda McManus was appointed as a nurse consultant, and established a special clinic for late presenters. Patients admitted as late presenters who require emergency dialysis and are diagnosed with end-stage renal disease (ESRD) are referred to Breeda who usually sees them on the same day.

She begins counselling and educating patients on the modalities of RRT. Once the patient and the family make a decision on the best treatment option for them,

a plan for the creation of access is made. Patients who decide to embark on haemodialysis are educated on their new diet and fluid intake regime; they are discharged on a line and are followed up by Breeda in the haemodialysis clinic.

Once these patients begin outpatient dialysis, they visit the late presenters clinic once a week as part of their regular dialysis regime. The purpose of arranging weekly visits to the clinic is to support and listen to the patients to alleviate any concerns and anxieties. The aim is to optimise the patients' treatment plans by reviewing the blood results and altering their drug or dialysis prescription as required. Education on diet and fluid intake regime supports the management of patients' treatment. The clinics allow time for discussing patients' future treatment options, referring them to the transplant clinic or to the surgeons to have a fistula established if appropriate.

Breeda found it straightforward to set up the clinic as the idea had immediate support from the renal team. She joined the existing clinic on Mondays and Thursdays, seeing those patients who had presented late, making it available to all patients on whichever cycle of days they dialyse. A pre-dialysis nurse covers for Breeda on days when she is away.

The only change in practice that was needed was to educate nurses on the wards about the new service and for which patients it was designed, thereby ensuring that the nursing staff referred appropriate patients to Breeda as soon as they were admitted.

What happened as a result?

The clinic provides a much better experience for patients, offering them specific help at a time of sudden and significant change in their lives. Patients' blood levels are optimised as quickly as possible, helping them to feel better and thereby improving their health outcomes.

Patients are supported to make decisions about their preferred modality of RRT and are quickly referred to the transplant clinic or for a fistula if appropriate.

Learning points

Relevant staff in secondary care need to be aware of:

- › the late presenters clinic;
- › which patients should be referred to the clinic, when and how.

In addition, late presenters need rapid access to advice on diet and fluid intake and, often, to the transplant clinic or specialists to create a fistula. Therefore, it is important to agree protocols with these specialist colleagues to ensure that the relevant procedures are undertaken as quickly as possible.

It is also important to audit and capture information about late presenters to identify:

- › the causes of and common reasons for late presentation;
- › ways to reduce the number of late presenters in future.

Key resources required for implementation

- › The Barts and The London Renal Centre benefitted from having a dedicated post to concentrate on late presenters.
- › Existing resources were used to deliver the clinic, with the development of processes and procedures to ensure the needs of late presenters are met swiftly.

Case-study 3: Nurse-led catheter insertion to increase use of peritoneal dialysis

Setting

The peritoneal dialysis (PD) unit at King's College Hospital NHS Foundation Trust in London.

The situation or problem

For people who need to dialyse, the benefits of home dialysis compared with in-centre dialysis are widely recognised:

- It is more convenient for patients, giving them control over their condition and life;
- It is more cost-effective for the NHS.

Peritoneal dialysis is an effective form of home dialysis, but its use is not as widespread as it could be.

The peritoneal dialysis team at King's have implemented various measures to encourage the use of peritoneal dialysis including working closely with:

- the low clearance clinic to ensure that patients coming onto dialysis are aware of peritoneal dialysis and can make an informed decision about the type of dialysis that will best suit their needs;
- a dedicated late presenters clinic to support patients who need dialysis urgently.

Evidence shows that patients tend not to change their dialysis type after they have started and in the past many late presenters would automatically go onto haemodialysis. One of the reasons for this is that, traditionally, the insertion of the catheter into the patient's peritoneum has been carried out by a surgeon under general anaesthetic. However, organising a theatre slot and ensuring the patient is fit for the anaesthetic can often take too long.

What action was taken?

Several peritoneal dialysis units now carry out the procedure under local anaesthetic in the clinic to avoid these delays, but it is usually done by junior doctors who soon move on elsewhere. At King's, the associate specialist undertook the procedure and acquired considerable expertise over time. When he announced

his retirement, the team decided to maintain the expertise within the unit, and a consultant nephrologist and nurse specialist in peritoneal dialysis underwent training to carry out the procedure.

The nurse and consultant attended the two-day course run by the Baxter Access Academy which goes through the procedure in detail and includes a simulated practice. The retiring associate specialist also underwent training to become a mentor so that he could support the "new" operators as they began carrying out the procedure.

Although it was relatively straightforward for the consultant to complete the training, for the nurse to begin carrying out the procedure, several documents had to be prepared for approval by the Trust including a competency framework and pre- and post-procedure patient information. The nurse also needed to have already undertaken training in advanced assessment for nursing practice and advanced consent, which were pre-requisites for carrying out the insertion of catheters under local anaesthetic.

What happened as a result?

The nurse carried out her first 10 procedures with the mentor in attendance, and has now carried out nearly 100 with a high success rate. The advantages of catheter insertion as an outpatient procedure under local anaesthetic are shown in Box CS3.1. However, the procedure is not suitable for everyone, particularly patients with a high body mass index (BMI).

Box CS3.1: Advantages of catheter insertion as an outpatient procedure under local anaesthetic when compared with catheter insertion by surgeon under general anaesthetic

- Quicker
- Safer
- More convenient
- Better experience for patients
- Cost-effective for NHS

Catheter insertion under local anaesthetic means that the patient stays with the peritoneal dialysis team throughout their entire journey and gives the peritoneal dialysis team complete control over how the catheter is positioned, where the exit site is, and how it looks. Patients can be much more involved and engaged, particularly with respect to the positioning of the exit site (e.g. such that it is not positioned directly beneath the belt for men or is positioned below the bikini line for women). The team believe that this is part of the reason why the unit has seen a fall in the number of exit-site infections since they began carrying out the procedure in this way.

Following the success of the nurse's role, another nurse from the peritoneal dialysis unit at King's is scheduled to undertake the training.

Learning points

Increasing use of peritoneal dialysis has required a range of measures, including:

- working with the low clearance clinic to support patients to make an informed choice;
- the establishment of a late presenters clinic to ensure that all patients have the opportunity to choose the type of dialysis that best suits their individual needs and circumstances.

It is important to give patients the time and space to make informed decisions. Evidence shows that people tend not to change their dialysis type once they have started. In the late presenters clinic at King's, it is explained to patients who need urgent dialysis that their initial type is only 'interim' and supports them to reach a considered decision over time.

When expanding a peritoneal dialysis service, it is advantageous if catheters can be inserted under local anaesthetic in the peritoneal dialysis clinic, avoiding the delay, inconvenience and costs of a referral to surgery. Concentrating experience within the peritoneal dialysis team at King's has allowed the team to build up expertise, which in turn has enabled them:

- To insert most catheters successfully;
- To carry out any follow-up management;
- To support each other when dealing with queries and/or concerns.

It is relatively straightforward for nurses to undertake the training to enable them to carry out the procedure, although detailed documentation and pre-requisite training is required beforehand.

Case-study 4: New pathways to ensure timely referral for transplant

Setting

The renal centre at Aintree University Hospitals NHS Foundation Trust covers a population of around 500,000 people across the North of Merseyside. It has about 200 dialysis patients and cares for many more with chronic kidney disease. Patients who are listed for transplant are referred to the transplant unit at the Royal Liverpool University Hospital.

The situation or problem

When appropriate, receiving a kidney transplant is the best form of treatment for patients who are approaching end-stage renal failure. Evidence shows that patients who have a transplant have a better quality of life and live longer than those who have dialysis treatment. Furthermore, patients who receive a pre-emptive transplant before they need to begin dialysis have better outcomes in terms of morbidity, mortality, quality of life and transplant survival than those who have a transplant after a period on dialysis.

However, there are many steps involved in transplantation and this means that many patients who might be suitable for a kidney transplant are not always identified, listed and prepared at an early enough stage to receive a transplant before they need dialysis.

In Renal Association guidelines, it is recommended that patients could receive a pre-emptive transplant or be placed on the national transplant list up to six months before their anticipated dialysis start date. However, it is difficult to predict when a patient will need a transplant because kidney disease does not always have a linear progression. Once a decision to explore transplantation has been made, the time taken to prepare a patient also varies. Tests need to be carried out to assess whether patients are suitable and fit enough for the procedure, including extensive cardiac screening in selected patients and assessment by transplant surgeons. Patients also need time to consider the risks and benefits of transplantation and the alternatives, so that they can reach a fully informed decision. If patients opt for a live transplant, potential donors also need to be assessed for suitability and be prepared for organ donation.

Consultant nephrologist, Dr Asheesh Sharma, and his colleagues at Aintree realised they could increase the level of support for patients that would enable them to receive transplants at an earlier stage. On investigation, they found:

- variation among clinicians in the stage at which referrals for transplant were made;
- there was no single referral pathway;
- the roles and responsibilities of each member of the clinical team with respect to transplant referrals were not clearly defined. This resulted in variation in the amount of information provided with transplant referrals, and the level of screening and patient education and discussion that had taken place prior to referral. Consequently, there were delays in the transplant listing process.

Reliance on the cardiology team to carry out screening was also identified as an issue.

It became clear that the prevailing culture in the renal centre tended towards dialysis being seen as the norm, with patients not receiving the information and education to make informed decisions in a timely manner. Part of the reason for this was the fact that the transplant unit was at another hospital and patients who had received a transplant did not transfer back to Aintree but remained under the care of the Royal Liverpool after transplantation.

What action was taken?

Dr Sharma and his colleagues successfully applied to NHS Kidney Care to take part in a project to improve timely listing for kidney transplant. Funding was received for a nurse specialist to work part-time for six months to audit current practices and support the implementation of a range of measures which could be self-sustaining, and to capture the learning that could be shared with other units.

The team established defined pathways, and developed a mandatory pro forma for the referral of patients for transplant. Use of the pro forma ensured that all the

necessary information gathering, local assessments, education and preparation were carried out before the patient was referred to the transplant unit, thereby avoiding delays.

Referrals for transplant were restricted to two pathways.

1. For patients already on dialysis, referrals were made through the day-case unit, where all the necessary tests and education were carried out.
2. Pre-dialysis patients whose kidney function had deteriorated to an agreed level [an estimated glomerular filtration rate (eGFR) of 20ml/min/1.73m² or less] were referred to a new multi-professional clinic.

At this clinic, all patients nearing advanced kidney disease are supported to make informed choices not just about whether to have a transplant, but also about whether to begin dialysis or move onto conservative care instead. Developing a greater focus on transplantation shifts the culture away from dialysis being seen as the norm. The clinic includes nephrologists, nurse consultants, dieticians, pharmacists and palliative care specialists to support patients whichever route they choose to take.

Staff across the renal centre were engaged in:

- › establishing the new clinic;
- › developing the new referral pathways;
- › raising awareness of the evidence about the benefits of transplantation;
- › helping to challenge established culture and perceptions.

All nurses in the centre cover the day-case clinic, and the extra training they have received to help prepare patients for transplant referral has also supported the change in culture.

In developing the new referral pathways, relationships between the renal centre and the transplant unit have been strengthened. The renal centre has also worked closely with a cardiologist, helping to streamline referrals

for screening. In turn, the cardiologist has developed a relationship with the transplant unit, building the unit's confidence in the quality of the information received when patients are referred.

What happened as a result?

There is increased identification at an early stage of patients who might benefit from transplantation, with fast referral to a dedicated clinic for assessment, thereby accelerating the whole process. It is expected that this will lead to an increased number of patients receiving transplants, including patients receiving them pre-emptively. Successful transplantation has considerable benefits for patients' health and quality of life; furthermore, it is a more effective use of NHS resources than dialysis.

Learning points

The improvements undertaken in the renal centre involved a series of simple practical steps that together make a real difference.

The key learning point is the need for clearly defined referral pathways that are tailored to the units involved.

Engagement has been essential throughout the process. Internal engagement was important:

- › To develop an agreed referral pathway;
- › To establish the new clinic;
- › To begin changing the prevailing culture.

External engagement with colleagues in the cardiology team and transplant unit was also important to implement some of the necessary changes.

Key resources required for implementation

Although support was received from NHS Kidney Care to audit existing practices and to help establish the new referral pathways and clinic, the changes are resource-neutral, designed to fit within the existing work of the renal centre, thereby ensuring that the changes will be sustainable.

Case-study 5: E-alerts to ensure timely response to acute kidney injury

Setting

Nottingham University Hospitals NHS Trust is one of the country's largest acute trusts, split between two sites.

The situation

There is growing recognition that acute kidney injury (AKI) is a serious problem. The results of studies suggest that as many as one in five people admitted to hospital as an emergency suffer from AKI and it has a substantial effect on patient outcomes and the use of NHS resources.

In 2009, key findings in the report of the National Confidential Enquiry into Patient Outcomes and Death (NCEPOD), entitled *Acute Kidney Injury: Adding Insult to Injury*,¹ included:

- only about 50% of all AKI patients received good care;
- there were significant delays in the recognition of AKI.

Mark Devonald, a consultant nephrologist at Nottingham University Hospitals NHS Trust, was asked to lead the Trust's response to the recommendations in the NCEPOD report. He already had a research interest in AKI, and with his colleagues, Christine Porter and Irene Juurlink, was carrying out a retrospective analysis of AKI incidence and outcome from the previous three years. They had established a series of algorithms to search the Trust's biochemistry database, examining patients' creatinine results to identify cases of AKI that had occurred.

What action was taken?

Mark and his colleagues realised they could modify the algorithms for use in real time. When a patient has a creatinine check, the algorithm could be used to identify current cases of AKI and to flag this to the patient's clinician.

Acute kidney injury is identified by an increase in a patient's creatinine level from their 'baseline' or 'reference' reading. The proportional increase indicates the stage of AKI. There are two internationally established definitions of AKI, known as RIFLE and AKIN, both based on a percentage increase in creatinine:

- RIFLE looks at an increase over seven days;²
- AKIN looks at an increase over 48 hours – AKIN also has the additional criterion of an absolute increase in creatinine of 26 µmol/L within 48 hours as an indicator of stage 1 AKI.³

The Nottingham University Hospitals' algorithms apply both the RIFLE and AKIN criteria and report the higher stage if there is a discrepancy between the two, increasing the sensitivity of the system for identifying cases of AKI.

Almost all acute patients at the Trust have a creatinine check on admission. The results of all biochemistry tests are automatically entered by the laboratory onto the Trust's information system, making them available to clinicians. As soon as they are entered, the system automatically checks the creatinine level against the patient's baseline reading.

The Nottingham University Hospitals' algorithms apply a particularly accurate methodology to establish the patient's creatinine baseline reading. Around 80% of acute admissions will already have one or more creatinine results on the Trust's biochemistry database, either taken at the hospital or via their GP. Based on evidence from the literature on AKI, the algorithm will take the lowest reading from the previous year as a baseline, making it more likely to be accurate in identifying potential AKI. It will also exclude any results taken in the seven days prior to admission, as these may already reflect increased creatinine levels due to acute illness.

1 National Confidential Enquiry into Patient Outcomes and Death (NCEPOD) (2009) *Acute Kidney Injury: Adding Insult to Injury*. <http://www.ncepod.org.uk/2009aki.htm>

2 RIFLE Classification for AKI: see Bellomo R, Ronco C, Kellum JA, Mehta RL, Palevsky P. Acute renal failure – definition, outcome measures, animal models, fluid therapy and information technology needs: the Second International Consensus Conference of the Acute Dialysis Quality Initiative (ADQI) Group. *Crit Care*. Aug 2004;8(4):R204-12.

3 Acute Kidney Injury Network (AKIN). <http://www.akinet.org/akinstudies.php>

For patients without a previous baseline creatinine reading, a theoretical value is calculated based on the use of the well-established MDRD equation.⁴ A normal level of renal function is assumed [estimated glomerular filtration rate (GFR) of 75ml/min/1.73m²] and the patient's age, sex and ethnicity are added to the equation to produce the theoretical baseline creatinine value. Using actual baseline creatinine values wherever possible increases the specificity of the system, thereby increasing the level of accuracy.

If the system identifies a potential case of AKI, the clinician will see a flag against the patient's results when they look them up on the information system. It will alert the clinician that the patient has AKI, which stage, and will refer the clinician to the AKI management and referral guidelines on the intranet. This means that cases of AKI can be managed locally and that specialist referral is made early, where appropriate. The guidelines enable all clinicians involved in acute patient care to provide the most appropriate care for patients with AKI.

As well as flagging any early indications of AKI on admission, each time a new creatinine result is put onto the system, the algorithms compare the latest result with the results from the preceding 48 hours and seven days to test against both RIFLE and AKIN criteria, respectively.

What happened as a result?

The e-alert system enables clinicians at Nottingham University Hospitals NHS Trust to detect more cases of AKI and to detect them much earlier. By indicating the stage of AKI and signposting the management and referral guidelines, it ensures that patients receive the most appropriate care in a timely manner.

Earlier detection means that patients can receive the right care much sooner, thereby improving outcomes and reducing mortality. Early identification can help to stop progression of AKI, which can be very serious for patients and expensive for the health service.

Learning points

An AKI alert system requires expert renal input, but most cases of AKI in large acute hospitals do not involve nephrologists. It is important to have input and feedback from a spectrum of acute specialties, including acute medicine, intensive care, general surgery, and orthopaedics. It is also important to involve junior doctors when developing an alert, because they are the clinicians who will see and act upon the alerts.

It took the team at Nottingham University Hospitals NHS Trust about a year and a half to develop, test and refine the algorithms. This included running the alert as a pilot system for one year.

Key resources required for implementation

Nottingham University Hospitals NHS Trust uses the WinPath laboratory information management system (LIMS). Laboratory results, including creatinine, are exported to the Trust's own 'NotIS' hospital information system, in which the algorithms work and the alerts are flagged.

In addition to the clinical team, it is essential to involve the biochemists and ICT experts who understand the laboratory and information systems in place in the Trust.

RESOURCES AND FURTHER INFORMATION

- How-to Guide. E-alerts ensure timely response to acute kidney injury.
http://www.kidneycare.nhs.uk/howto_guides1/aki_ealerts/
- Mark Devonald is willing to share the algorithms with other Trusts, but each Trust would need to work with their ICT staff to put the appropriate coding into their specific hospital information system. Contact: Mark Devonald, Consultant Nephrologist, Nottingham University Hospitals NHS Trust, mark.devonald@nuh.nhs.uk

⁴ The MDRD equation is one of several equations used for estimating GFR. The use of the abbreviated MDRD (Modification of Diet in Renal Disease Study) is recommended by NICE and the Renal Association (UK).

Glossary of Essential Terms

Introduction

Much of the disagreement that occurs during the commissioning or management of services arises because different people use the same term but have a different understanding of its meaning. This Glossary is provided to help develop a shared or common language. If there is a clear, short or memorable definition from the literature, this has been cited and presented in italics; where definitions in the literature do not meet any of these criteria, Right Care has composed and provided a definition.

Access to healthcare

Facilitating access is concerned with helping people to command appropriate health care resources in order to preserve or improve their health. There are at least four aspects.

1. *If services are available, in terms of adequate supply of services, then a population may 'have access' to health care.*
2. *The extent to which a population 'gains access' to health care also depends on financial, organisational and social or cultural barriers that limit utilisation. Thus utilisation is dependent on the affordability, physical accessibility and acceptability of services and not merely the adequacy of supply.*
3. *The services available must be relevant and effective if the population is to 'gain access to satisfactory health outcomes'.*
4. *The availability of services, and barriers to utilisation, have to be evaluated in the context of differing perspectives, health needs and the material and cultural settings of diverse groups in society.*

Source: Gulliford M et al (2001) *Access to Health Care. Report of a Scoping Exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)*. http://www.kcl-phs.org.uk/martin/reprints/accessscopingexercise_report.pdf

Appropriate

A procedure is termed appropriate if its benefits sufficiently outweigh its risks to make it worth performing ...

Source: Kahan JP et al (1994) Measuring the necessity of medical procedures. *Medical Care* 32: 352-365

Average, see **Mean**

Confidence intervals

Confidence intervals give the range within which the true size of a treatment effect (which is never precisely known) lies, with a given degree of certainty (usually 95% or 99%).

Source: Evans I, Thornton H, Chalmers I (2006) *Testing Treatments. Better Research for Better Healthcare*. The British Library.

Costs

Cost is not solely financial. Cost may be measured as the time used, the carbon produced, or the benefit that would be obtained if the resources were used for another group of patients (i.e. the opportunity cost).

Deprivation

Deprivation is a concept that overlaps, but is not synonymous with poverty. Absolute poverty can be defined as the absence of the minimum resources for physical survival, whereas relative poverty relates to the standards of living in a particular society at a specific time. The different concepts of deprivation include the following:

- *Material deprivation, which reflects the access people have to material goods and resources. Access to these goods and resources enables people "to play the roles, participate in relationships and follow the customary behaviour which is expected of them by virtue of their membership in society" (as described by Townsend).*

- *Social deprivation has been separately distinguished as relating to people's roles and relationships, membership and social contacts in society.*
- *Multiple deprivation relates to the occurrence of several forms of deprivation concurrently, such as low income, poor housing, and unemployment. This can be particularly stressful for families.*

Source: http://www.show.scot.nhs.uk/publications/isd/deprivation_and_health/background.HTM

Effective care

The extent to which an intervention, procedure regimen, or service produces a beneficial outcome under ideal circumstances (e.g., in a randomized controlled trial).

Source: Canadian Agency for Drugs and Technologies in Health (2009) Optimal Therapy Report: Cost effectiveness of blood glucose test strips in the management of adult patients with diabetes mellitus. Volume 3, Issue 3.

Efficiency

See also **Productivity**

... efficiency can be defined as maximising well-being at the least cost to society.

Source: Mitton C, Donaldson C (2004) *Priority setting toolkit. A guide to the use of economics in healthcare decision making.* BMJ Publishing Group.

Equity

Equity is a subjective judgment of fairness.

Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Source: Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June-22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948. The definition has not been amended since 1948. <http://www.who.int/suggestions/faq/en/index.html>

Health needs

... objectively determined deficiencies in health that require health care, from promotion to palliation.

Source: World Health Organization. Health Systems Strengthening Glossary. http://www.who.int/healthsystems/hss_glossary/en/index.html

Inequalities in health

Inequalities in health are objectively measured differences in health status, healthcare access and health outcomes.

Input, Output and Outcome

Input is a term used by economists to define the resources used, such as the number of hospital beds, to produce the output, such as the number of patients admitted per bed per year.

The economists' terminology is different from the language utilised in quality assurance, in which the terms structure, process and outcome are used. Input equates to structure and process, i.e. the number of beds and the number of admissions per bed, respectively. However, the outcome is distinct from the output. Outcome includes some measure of the effect the process has had on the patients, for example, the number of patients who were discharged to their own home.

Integrated care

Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions such as through use of shared guidelines and protocols.

Source: Kodner DL, Spreeuwenberg C (2002) Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2: 1-6.

Mean (average)

The mean is the sum of values, e.g. size of populations, divided by the number of values, e.g. number of populations in the sample.

Medical care epidemiology

... studies the use of health care services among populations living within the geographic boundaries of "natural" health care [populations].

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care.* Oxford University Press.

Network

If a system is a set of activities with a common set of objectives, the network is the set of organisations and individuals that deliver the systems.

Outcome, see Input, Output and Outcome

Output, see Input, Output and Outcome

Patient Reported Outcome Measures (PROMs)

Patient Reported Outcome Measures measure quality from the patient perspective. ... PROMs are measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time. The health status information collected from patients by way of PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to NHS Patients.

Source: NHS Information Centre for health and social care. Patient Reported Outcomes Measures (PROMs). What are PROMs? <http://www.ic.nhs.uk/proms>

Population medicine

Population medicine is a style of clinical practice in which the clinician is focused not only on the individual patients referred but also on the whole population in need.

Preference-sensitive treatment decisions

Preference sensitive treatment decisions involve making value trade-offs between benefits and harms that should depend on informed patient choice.

Source: O'Connor AM et al (2007) Toward the 'Tipping Point': Decision aids and informed patient choice. *Health Affairs* 26: 716-725.

Preference-sensitive care

... elective, or "preference-sensitive care", interventions for which there is more than one option and where the outcomes will differ according to the option used because patients delegate decision making to doctors, physician opinion rather than patient preference often determines which treatment patients receive. I argue that this can result in a serious but commonly overlooked medical error: operating on the wrong patients – on those who, were they fully informed, would not have wanted the operation they received.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

Productivity

See also **Efficiency**

Productivity is the relationship between inputs and outputs, such as the number of operations per theatre per year; efficiency is the relationship between outcomes

and inputs, such as the number of successful operations per theatre per year.

Quality

Quality is the degree to which a service meets pre-set standards of goodness.

Source: Donabedian A, personal communication.

Quality of life¹

... individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Source: World Health Organization (WHO) Programme on Mental Health. WHOQOL: Measuring Quality of Life. The World Health Organization Quality of Life Instruments (The WHOQOL-100 and the WHOQOL-BREF). http://www.who.int/mental_health/media/68.pdf

Range

The range is the difference between the highest and lowest value in the sample. The range provides a crude measure of the spread of the data.

Safety

Patient safety can, at its simplest, be defined as: The avoidance, prevention and amelioration of adverse outcomes or injuries stemming from the process of healthcare. ... the reduction of harm should be the primary aim of patient safety, not the elimination of error.

Source: Vincent C (2006) *Patient Safety*. Churchill Livingstone.

Shared decision-making

In a shared decision, a health care provider communicates to the patient personalized information about the options, outcomes, probabilities, and scientific uncertainties of available treatment options, and the patient communicates his or her values and the relative importance he or she places on benefits and harms.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

1 Examples of other quality of life definitions can be found at: <http://www.scotland.gov.uk/Publications/2006/01/13110743/11>

Standard deviation

See also **Variance**

The standard deviation is a measure of spread, and is the square root of the variance.

Standards

A minimum level of acceptable performance or results or excellent levels of performance or the range of acceptable performance or results.

Source: Kohn LT, Corrigan JM, Donaldson MS (eds) Committee on Quality of Health Care in America, Institute of Medicine (2000) *To Err is Human. Building a Safer Health System*. National Academy Press, Washington.

Supply-sensitive care

It differs in fundamental ways from both effective care and preference-sensitive care. Supply-sensitive care is not about a specific treatment per se; rather, it is about the frequency with which everyday medical care is used in treating patients with acute and chronic illnesses. Remediating variation in supply-sensitive care requires coming to terms with the "more care is better" assumption. Are physician services and hospitals in high-cost, high-use regions overused?

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

System

A system is a set of activities with a common set of objectives for which an annual report is produced.

Unwarranted variation

Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press.

Value

... value is expressed as what we gain relative to what we give up – the benefit relative to the cost.

Source: Institute of Medicine of the National Academies (2008) *Learning Healthcare System Concepts v. 2008*. The Roundtable on Evidence-Based Medicine, Institute of Medicine. Annual Report.

Variation

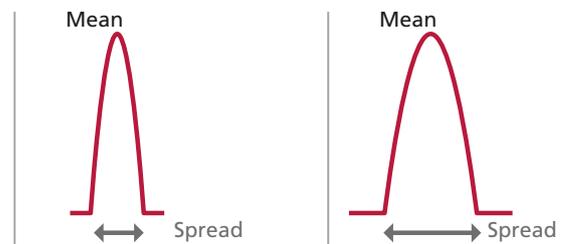
Everything we observe or measure varies. Some variation in healthcare is desirable, even essential, since each patient is different and should be cared for uniquely. New and better treatments, and improvements in care processes result in beneficial variation.

Source: Neuhauser D, Provost L, Bergman B (2011) The meaning of variation to healthcare managers, clinical and health-services researchers, and individual patients. *BMJ Qual Saf* 20 (Suppl 1); i36-i40. doi: 10.1136/bmjqs.2010.046334

Variance

See also **Range**

The variance is another measure of spread, which describes how far the values in the sample lie away from the mean value. It is the average of the squared differences from the mean and is a better measure of spread than the range.



This figure illustrates how two populations may have the same mean value, but different degrees of variation or spread: the second population shows greater variation than the first.

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