Renal replacement therapy, coronary artery surgery and HIV/AIDS in Camden and Islington

Geographical Area covered: Camden and Islington
Focus: Case studies focusing on the use of national indicators

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Editorial comments on how case study is linked to improving health outcomes: (also published in Volume 1)

In this case study on renal replacement therapy, coronary artery surgery and HIV/AIDS McCarthy highlights the difficulty of obtaining local population based health outcomes. In many cases such information does exist but clinicians are reluctant to provide this to purchasers. Although outcome data are provided to national databases such the European Dialysis and Transplant Association database and the UK Cardiac Surgery register there are few incentives for these provider led organisations to disseminate the information to health authorities. (Moreover postcode and district of residence are often not collected). HIV/AIDS information could be made available by district of residence in addition to provider based information. The author suggests that the NHS Executive and DoH have a role to play in making this information available locally.

Abstract (also published in Volume 1)

District population health measures for three clinical areas are considered in this chapter. For renal replacement therapy and coronary artery surgery, local population-based information was compared with national guidance to consider whether the Health Authority should identify a preferred provider. For HIV/AIDS, local population-based information was sought from national systems for the Health Authority to focus on the health needs of the resident population.

Levels of renal replacement therapy were at national target levels, but coronary artery surgery rates were below. Only limited outcome information was available to the Health Authority, although more was collected by local units. While improved information was requested within specifications, little new outcome data was gained from contracting meetings. However, during the period there was a substantial rise in treatment rates (for both areas) as a result of provider demand.

For HIV/AIDS, very limited population-based data were available. Calculation of data held by Communicable Disease Surveillance Centre allowed an improved population focus, and data relevant to prevention was also collated through commissioning a local university department. However, population-based information on patient survival, or intermediate such as new HIV infection rates, were not available from local providers.

Population outcome data exist in these fields but are not being used. The Department of Health should review requirements for population-based data to assist local public health practice for commissioning and give attention in performance management to these data.

Introduction:

Why this clinical area was chosen:

This paper describes district population health outcome assessments in three clinical areas - renal replacement therapy (RRT), coronary artery surgery (CAS) and HIV/AIDS. Each clinical area is relatively discrete and has had a national programme of service development, investment in research and development, and expanding service provision. The purpose of the RRT and CAS studies was to identify levels of provision and available outcome measures, and advise whether the district should choose a ‘preferred’ provider for these services. For HIV/AIDS, the purpose was to identify information about the
local population rather than by provider.

Camden and Islington Health District, in north central London, has a resident population of about 360,000. The district is within the top decile on the Jarman deprivation index, and the annual turnover of the local population is estimated at ten times the national average. The population ethnic mix is similar to the London average of 20%, but encompasses a wide range of ethnic groups including people from west Africa, the Caribbean, Bengal and from middle eastern and far eastern countries. There is a high rate of homelessness, and waiting lists for public housing.

There are three major undergraduate teaching hospitals within the district’s boundaries (University College London Hospitals, Whittington Hospital, Royal Free Hospital), each serving adjacent districts as well as Camden and Islington. There are also postgraduate hospitals and institutions, some now absorbed within the larger hospital trusts, serving both London and national catchments. There is a large ‘community’ health service Trust which manages both inpatient and community-based care for non-acute specialties and HIV/AIDS services for two-thirds of the district. Of the 100 general practices in the district, half are single or double-handed.

Deprivation and teaching hospital costs in Camden and Islington are balanced by high per capita NHS expenditure. The district has 13% more weighted capitation funding than the average for districts in England (although a level similar to the average in Scotland), so that service developments have to be compared against the cost-effectiveness of existing provision. Funding for HIV/AIDS, allocated through a national top-slice, is second highest in the country.

An overview Population Health Needs Assessment, published in January 1993, was the basis for the District’s Health Strategy, published in October 1994. At the same time, smaller specific needs assessments and analyses were undertaken: those for renal replacement therapy and coronary artery surgery were started in 1992, and updated in 1994 and 1996. Work on HIV/AIDS was undertaken in 1995/96 as, with the abolition of Regional Health Authorities in 1996, District Health Authorities would be responsible for the statutory Annual Report to Parliament under the 1988 AIDS (Control) Act.

Further information that was required:

A) Renal replacement therapy

There are three main methods of renal replacement therapy for end stage renal failure - haemodialysis (at home or in a hospital unit), continuous ambulatory peritoneal dialysis (CAPD) and kidney transplantation. The Region’s hospital admission information system was interrogated, using chronic renal failure and treatment codes, revealing 116 patients. Many patients had multiple admissions, and the search needed to distinguish those patients who were receiving dialysis for acute renal failure from those with end stage renal failure. The renal units in the three main local provider hospitals were then contacted directly. With their computer-based systems, they identified 148 patients, which, as they included well patients with transplants, was considered more reliable. The number of new patients taken on to RRT in the preceding year was not available, nor data on quality or outcome. The regional transplant coordinator was unable to provide any data on transplants for Camden and Islington residents, only data by providers.

National guidance from the UK Renal Association had set a target in 1990 of 80 new patients per million adults under the age 80 (incidence). Local data were only available for currently treated patients (prevalence). The North Thames regional rate was 78 ppm, and - given the local accessibility of renal units - it seemed likely that Camden and Islington also reached it. In this early period of the NHS reforms, it was not possible to determine levels of RRT from provider invoices, so the district assessment depended on the data from local renal units. It was concluded (Walker 1992) that, while existing levels of treatment appeared satisfactory, there was likely to be demand for expansion in the future; and that there was no information to support changing the existing pattern of service provision.

In 1994, because of demands from providers to expand resources, a new estimate of needs and provision of RRT was made, with a particular look at costs of local providers. The report (Hardie and Basnett 1994) identified the likely continued expansion of provision because of changing indications for acceptance and the accumulation of surviving patients. The report was unable to explain the cost differences between local units, and could not advise on a preferred provider given the lack of information for evaluation. For the next contracting round, an individual service specification for RRT was proposed, with information in a standard format to be requested from each provider unit.

In 1996 a further review of RRT purchasing was undertaken (Turbitt 1996), overlapping in time with publication of advice from the NHS Executive (EL(96)35) on purchasing for renal services. The EL provided more detailed epidemiological information (age-group and ethnicity-specific incidence rates), allowing a closer match against the local population profile. RRT patients were divided into three (standard, medium and high) risk groups, with expected national rates of new cases, current prevalence and future prevalence. Data on new cases was now available from the local renal units, so it was possible to show that the 1995/96 Camden and Islington level of treatment, 188 patients (670 per million), was at the high end of estimated need, and the 33 (118 patients per million) new
acceptances were above the Renal Association’s target level of 80-100 ppm (even allowing for the ethnic mix).

No survival rates were provided by any local renal unit for RRT. One of the three units provided data on renal transplants by residence, from which 1-year survival rates for transplant patients and grafts could be calculated. The same unit also provided peritonitis rates for CAPD, reporting levels within the Renal Association’s guidelines. The other units did not provide these data.

B) Coronary artery surgery
The district’s Annual Public Health Report in 1991 reported that heart disease deaths rates were slightly below the national average. The Department of Health had recommended in 1990 an annual rate of coronary artery bypass grafts (CABG) of 300 per million. Higher rates, from 400 to 700 per million, had been recommended by a consensus conference of the Kings Fund and by the Royal College of Physicians and Surgeons.

Again, data on cardiac surgery was drawn from the Region’s hospital admission information system, and followed by direct contact with the local coronary surgery units. There were 65 CABGs out of 103 open heart operations recorded for 1991 (other operations included valve replacement and congenital defects). An estimated further 18 were performed by two other London hospitals which did not provide patient information to the Regional system, and there were also an unknown number of private operations. The total, 83 operations, gave a rate of 240 per million. This was above the national average (220 ppm) but below recommended levels.

The two cardiac units both kept audit data for the national cardiac surgery register, but patients were not identified by district of residence. For the two hospitals, total CABG operations in 1991 were 449 and 345, while 30 day mortality for CABG were 1.1% and 2.0% respectively.

It was concluded that Camden and Islington residents had average access to cardiac surgery units. No proposal was made to expand the contracted level, but a recommendation to improve the quality of data from existing providers.

However, by 1995/96 the number of coronary artery operations recorded for Camden and Islington residents had increased substantially: there were now 138 CABGs (a 40% increase) and 45 percutaneous transluminal coronary angioplasties (PTCAs). This fully achieved the Department of Health’s 1990 target, but, by this time, guidance had been revised upwards, so that the levels were below the new targets for the District of 160 CABGs and 100 PTCAs.

More detailed information about patients had again to be requested from the two cardiac units, as it had not been received through contracts. Only one of the two providers made the information available - the other declined, citing a ‘change in computing systems’ as the reason. CABG 30 day mortality was at similar levels as previously. Again, no information was available on pre-surgery risk categories of patients treated.

C) HIV/AIDS
In contrast with the capitation funding introduced for most NHS services in 1991, the Department of Health continued to base its annual allocations for HIV/AIDS on provider activity, irrespective of where the patient lived. The Department of Health divided HIV/AIDS funds into two parts. The largest proportion - over 90% nationally - was allocated to ‘treatment and care’, which included in hospital inpatient and outpatient services, mostly on AIDS care but also supporting expansion of GUM, drug misuse and haemophilia replacement therapy (plasma products free of possible HIV infection). A much smaller proportion of the funds was allocated to local health promotion, according to capitation.

The allocations were based on hospital reports new laboratory HIV diagnoses and AIDS, and thus gave incentives for hospitals to provide testing facilities and retain patients for treatment rather than return them to their local hospital. Table 1 shows that allocations did not relate to numbers of HIV/AIDS cases in the resident population (they were based on historical patterns of provider activity), while prevention allocations related neither to capitation nor HIV prevalence in the population.

| Table 1: Inner North London districts: HIV/AIDS allocations 1995/96 |
|------------------|----------------|----------------|----------------|
|                  | AIDS cases per | Total           | Treatment       | Prevention     |
|                  | million 1995   | £m              | £ per case      | £ per resident |
| Barnet           | 115            | 1.4             | 12              | 1.1            |
| Brent & Harrow   | 98             | 5.1             | 52              | 1.1            |
| Camden & Islington | 226          | 23.9            | 105             | 2.8            |
| Ealing, Hammersmith & Hounslow | 194 | 13.2 | 68 | 1.1 |
| East London & City | 148          | 19.1            | 129             | 1.3            |
| Enfield and Haringey | 82           | 3.0             | 36              | 1.1            |
| Hillingdon       | 51             | 1.8             | 35              | 1.1            |
| Kensington, Chelsea & Wesminster | 393 | 47.8 | 121 | 1.1 |
Traditional HIV/AIDS information was to monitor the epidemic and expenditure nationally. The Communicable Disease Surveillance Centre (CDSC) created a system of voluntary notification of AIDS cases from clinicians and laboratories, while Regions reported on money allocated to providers. These became linked: more money was directed to providers with rising numbers of AIDS cases and laboratories with new positives. CDSC decided to record names of patients with AIDS by Soundex codes (to allow linkage) and post code: data were collected for new AIDS cases and deaths. In contrast, HIV positive tests were reported from the laboratories anonymously. From 1993 a system recording all patients under treatment - pre-symptomatic, AIDS symptoms and full AIDS disease - was also started, called the ‘information exchange’, collected by CDSC from providers and returned to them.

A report on HIV/AIDS in district residents from the Director of Public Health was presented to the Health Authority in September 1995 at the same time as the traditional provided-focused AIDS Control Act:

- CDSC reported the number of people dying with AIDS by district of the reporting consultant. Figure 1 shows these data, and the quite different numbers for district of residence. (Numbers of deaths from OPCS, by residence at death, were lower still, reflecting lack of recording on death certificates). Numbers of Camden and Islington resident new AIDS cases had roughly stabilised from 1991.

![Figure 1: Number of deaths in AIDS patients 1988-1995 (patients attending Camden and Islington services at the time of their AIDS diagnosis, and all Camden and Islington residents wherever treated)](image1)

- The number of all cases in treatment resident in the district was available through the CDSC ‘information exchange’. This new system, introduced in 1993, recorded numbers in treatment by three categories - pre-symptomatic, pre-AIDS and AIDS - and also gave the postal district for all cases, and numbers by year of first diagnosis. The number of resident people with HIV under treatment or care rose slowly between 1993 and 1995 (figure 2); but these data gave no information on length of care, numbers joining/leaving the district since the previous year, treatment regimes or survival, either crudely or stratified by CD4 count (a prognostic factor).

![Figure 2: Number of Camden and Islington residents under treatment for HIV/AIDS 1993-1995](image2)
The number of residents infected with HIV was unknown (because the laboratories do not return information on residence to CDSC within the confidential reporting mechanism). Local laboratories recorded a substantial rise in 'new HIV reports' (without residence data) - from 443 in 1994 to 697 in 1995, at odds with the treatment and case reporting data.

The relative expenditure on treatment compared with prevention in the Region's allocations to each district in North Thames (table 1) was discussed, and was subsequently reported in the press. Whether expenditure on HIV/AIDS care was high compared with other NHS priorities was also raised as a concern.

A study was commissioned from University College London academic department of GU Medicine to provide information on risk behaviour in local clinics (not necessarily local residents), risk behaviour and HIV prevalence in intravenous drug misusers (drug clinic attenders are expected to be residents, but this is not corroborated), and a special survey of sexual behaviour of people attending gay pubs and clubs in Camden and Islington (again, the majority not local residents but people targeted by local prevention services) (Nardone and Mercey, 1995).

Data validity studies:
The analyses presented here used routine information sources supplemented, where available, by local clinical data sets. No other validation studies were made on the data.

Summary findings from initial work:

Changes which were made:

A) Renal replacement therapy
The RRT review in 1992 answered the question initially set. RRT was at optimum levels, and appeared accessible. There was no clinical evidence to chose contracts with one provider rather than another, as none provided satisfactory information for such a judgement. However, clinicians continued to accept patients onto RRT programmes, and the increases in RRT activity were agreed by contract managers. Following the 1994 review, a renal services specification was developed for 1995/96 which was welcomed by both providers and commissioning staff, but did not set target levels for treatment. By 1996, after four annual contracting rounds, expenditure on renal replacement therapy had increased by far more than the annual increase in NHS funding to the district, and to levels greater than nationally recommended.

B) Coronary artery surgery
For coronary artery surgery the picture was different. Although both provider hospitals identified CAS within their contract portfolio, there was no separate contract or service specification. There appeared to be a shortfall in CABG operations for Camden and Islington residents compared with expected levels.
However, within the annual contracting round, the level of CAS also increased considerably over four years. Following a review of the District's coronary heart disease contracting in 1995 by the Audit Commission's District, using their national guidelines (Audit Commission 1995), it was agreed that an overview of commissioning for coronary heart disease should be presented to the Authority in late 1996, with the information on performance of CAS forming a part of this report.

C) HIV/AIDS

In January 1996 the Department of Health announced that allocations for HIV/AIDS treatment and care would be cut for all districts by 7.8% in 1996/97, (with prevention allocations maintained at existing levels). A meeting was held between district staff and clinicians and business managers from the two main provider Trusts to discuss the local implications of this cut. The financial effects on residents with HIV/AIDS could not be assessed, as districts continued to receive treatment and care allocations by provider unit. During contract negotiations, agreement was reached to manage within new budget levels. The health outcomes of these choices were not quantified.

The Health Authority also contracted for an independent public health medicine consultant to review HIV/AIDS treatment and care services in the district. The consultant's report identified a lack of adequate cost and outcome information, differences in policies between provider units, and the need to involve general practitioners more in HIV/AIDS care. The report was presented to the Health Authority in September 1996, and a seminar in November to a wider audience started a debate on cost-control.

How changes will be monitored:

These case studies are three examples of monitoring and surveillance data that should be readily available for public health medicine practice. They illustrate, however, the lack of adequate local information, even in health fields where disease-specific analyses have become standard at national level.

The initial surveillance was valuable in suggesting that no commissioning priority should be given to renal replacement therapy or coronary artery surgery, in contrast to other areas identified through the population health needs assessment where there was either unmet need or concerns that reflected particular inner London issues. These included drugs and alcohol (with high identified needs, stagnant resource levels and gross disparities of provision across the district), mental health care (with high levels of expenditure on both inpatient and residential care and lack of acute community services), physical disability (where several reviews had floundered from lack of subsequent administrative action) and HIV/AIDS, as well as smaller clinical areas including diabetes shared care, genetic screening for haemoglobinopathies and child psychiatry services. It was therefore perhaps surprising to find that, over the next four years, expenditure on renal replacement therapy and coronary artery surgery had both increased at rates far greater than the annual increase in district resources, since there had not been active discussion on this prioritisation within the Health Authority.

On the other hand, the small studies revealed that data sources do exist, or potentially exist, for the outcome information that would make commissioning more exact. For both RRT and CAS, local providers collected far more information in their own computer-based data systems than was released to the Authority. They provided the data to national databanks - the European Dialysis and Transplant Association Register, the UK Cardiac Surgery Register and the British Cardiovascular Intervention Society Register - but not, even on special request, to the local district public health department.

Monitoring HIV/AIDS in Camden and Islington is more pressing than monitoring RRT and CAS for three reasons: HIV is a new epidemic that requires new service measures to control; levels in Camden and Islington are among the highest in the country; and the cost-effectiveness of treatments is much lower while the cost per patient treated may be higher. It was of great concern to find that primary data for monitoring HIV/AIDS at local level did not exist (eg new HIV positives, survival times) or only very recently and with poor reliability (HIV patients in treatment). For a disease that had so much resource put into treatment of an incurable disease, very little attention appeared to have been given to measurement of district level outcome. It was disappointing that the Department of Health’s guidance for the 1996 District AIDS Control Act Reports required the old forma, still based on providers rather than local residents.

Resource Implication:

The three studies reported here were programmed work of the public health department within the health authority. The renal and coronary artery studies were part-time work of three registrars in public health (each for some months during the three study years), supervised by a public health consultant. The HIV/AIDS review was part-time work by the Director of Public Health for two months each in two years.

Practical lessons learnt:
The main lesson from this study is that, in three important areas of clinical practice, detailed population outcome information that is held by clinicians is not available to public health departments for population health commissioning, and there are few incentives to clinicians to reveal this information. The Department of Health may wish to consider its role in ensuring the availability of information at local level for public health practice.

In 1996, the NHS Executive circulated ‘Renal purchasing guidelines’ (EL(96)35) which expects Health Authorities to review their contracting for renal replacement therapy. The guidance does not mention outcomes, but a section entitled ‘quality’ recommends the Renal Association’s published standards and audit measures (Renal Association, 1995). That document includes, among others, correction of anaemia, blood pressure control, hospitalisation and mortality rates, and survival as quality measures attainable through audit. If renal units are following guidelines of their own professional association, these data should be available from local units. Equally, data being supplied to the EDTA register could also be made available to commissioners.

For coronary artery surgery there is no guidance from the NHS Executive. The Audit Commission’s report on coronary heart disease commissioning gives indicative levels of coronary surgery, but does not propose quality measures. Results from the national databanks kept by professional associations are published in professional journals, and suggest that outcome information could be available, but may be only at 30 days after surgery; one year survival, symptomatic and functional data would be preferable, and might be gained through a postal follow-up to the GP and patient.

Paradoxically, in these three clinical areas, in contrast to much of the NHS, outcomes were undoubtedly being measured; papers were being published, theses written. But the clinicians were reluctant to share this with the Health Authority. While NHS funds contributed to data collection and supported sizeable academic departments, commissioning administrators did not require outcome data as part of their contract negotiations. Clinical audit was not focused by the Health Authority on these areas, because providers were asked to choose their own agendas for audit as long as they included some clinical areas on national directives agendas (eg thrombolysis times, glue ear operations).

One aspect of these services is the relatively small proportion of local patients compared with the units’ total activity. For RRT, CAS and HIV/AIDS Camden and Islington district residents were a minority of all patients treated by the units (for HIV/AIDS care, but not for RRT and CAS, a substantial minority of local residents also went to other providers for treatment). In contrast to most districts, where providers are dependent on the local purchaser, in Camden and Islington the district has several powerful suppliers, and is only a minor partner. Purchasing alliances have been suggested as a means of greater power over providers, but were not used in this instance. It can be acknowledged that, if the local district is only a minor purchaser, clinicians may express less concern than if the district is a major local purchaser.

While the public health department tried to provide some relevant information, commissioning in these areas was essentially driven by finance rather than needs or outcomes. For RRT and CAS, extra resources were agreed by contract managers as a result of providers describing clinical ‘pressures’: cost-effectiveness or outcomes-based analysis was not used. For HIV/AIDS, the lack of implementation of the NHS reforms allowed the Department of Health to continue funding directly to providers without population need or outcome information.

**Conclusion:**

Population-based outcomes-led contracting should have been a major development of the NHS reforms. In contrast with previous structures, the new NHS districts are responsible for the same population across the full range of NHS care - prevention, GP treatment, hospital, long-term care - and a population register for all these patients is held by the DHA. Three reasons can be postulated for the limited use of outcomes at district level in these clinical areas: clinicians did not want to provide them to the Health Authority; commissioning administrators do not know how to use them; and the NHS Executive performance monitoring is focused on ‘activity’ and ‘efficiency’ data such as patient episodes and waiting times rather than standards of health in the population.
The reluctance of clinicians to cooperate in outcome measurement provision may be peculiar to Camden and Islington. The district has many clinicians - perhaps 500 consultants in the various hospitals - and some are as concerned with national as with local services. Trust administrators rarely involve clinicians in contract discussions, so they also rarely meet commissioning staff. Health Authority commissioners will not press for clinical information if they do not know how to deal with it. Thus, on the rare occasion a public health doctor seeks out a specific piece of provider information, clinicians tend to be both defensive and cautious. It is easier to say the information is not available than to provide it to someone who may use it in an unexpected way. It could be said that the public health department should have better, long-standing relationship with clinicians; but, this is difficult to achieve in any but a small number of specialities and it was the nature of these relatively ‘quick’ analyses that they were not built on long-standing contacts.

In the earlier years of the NHS reforms, the term ‘health gain’ was used. Although not euphonious, the term had several benefits: it emphasised health rather than health services, health status rather than activity; and change rather than a single static measure. Unfortunately, health gain seems to have been lost as an objective, and patient-level process or activity measures are preferred. Many NHS administrators lack training in clinical benefits (outcomes) and population approaches (considering untreated as well as treated patients, prevention as well as treatment). The focus of administrators often appears to be to ‘balance the books’ by taking into account the range of ‘pressures’ put on them by clinicians and other managers.

Lastly, the three case studies described here also raise the issue - how can the Department of Health demonstrate more interest in outcomes in the NHS? Most Health Authorities have probably commissioned RRT, coronary surgery and HIV/AIDS over the past five years without using outcomes information. In contrast to information required for the Patient’s Charter, the NHSE gives little encouragement to districts to value information on survival or health status of patients after major operations or on continuous therapy. In squeezing management costs, the NHSE may also be signalling that it does not want extra resources being spent on finding or using such information. Without greater support, it will continue to be difficult, at district level, to endure that population outcome assessment is used in health commissioning.

▼References:


▼Organisational Context: