# Chapter 23: The Next Steps

## *Introduction*

Throughout this year the Renal Registry has been helping the Department of Health with the data to support a 5 year plan for renal services and has also completed the national renal review. The Registry has also had liaison with the Kidney Alliance supporting the shadow national service framework. Other activities include links with the UK Diabetic Registry, UK National Quality Assurance Scheme, and the NHS Information Authority. In the UK there are now 4 research registrars working in conjunction with the Renal Registry. These registrars have been funded locally and it is hoped that more renal units will take advantage of the data held by the Registry.

The three annual reports of the Renal Registry have confirmed the feasibility of the exercise of regular sequential large volume data collection from renal units. A database is developing with detailed information on the day-to-day treatment of patients with renal failure. The consistency of the data as the Registry grows in size suggests the data is reasonably robust and representative of the UK as a whole. Valuable data for planning the future has been obtained, useful comparative audit has been presented, and the data is beginning to raise questions and give new insights on clinical practice. However the Registry is still in early stages of its development. It must continue to develop in the following areas.

## *Increased participation.*

The Registry is continuing to expand. The ultimate aim is to include all patients in the UK on Renal Replacement Therapy. The Registry remains voluntary. In this way, with the funding by individual renal units, it can remain an organisation under the umbrella of the Renal Association independent of the Department of Health and industry. Nevertheless, the Registry's activities are strongly supported by the Department of Health, which encourages participation. Many commissioners are including participation in the Registry as part of their contract with renal units. It is important that as many units as possible join the registry. This will improve the usefulness of the data. It will also enable it to continue with the present structure managed by the renal community in liaison with patients and other groups, and not be forced into becoming a mandatory exercise outside the control of nephrologists.

## *Improve data quality*

Some important elements of data return are poor. The most critical items for the usefulness of the data are co-morbidity at start of renal replacement therapy, serum creatinine at start of therapy, patient weight at start of therapy, and ethnic origin. Without these items survival data, and analysis of factors influencing outcomes are greatly reduced in value. Efforts will be made during this year to help units to improve return of these items. The Registry is also exploring the possibility of a validation exercise within renal units to check the data accuracy.

## *Expand the database*

The database has been created to include data in addition to that on renal replacement therapy. The possibilities of beginning to collect other data, perhaps on diabetes in liaison with the diabetic registry, will be explored.

## *Complete the audit cycle*

The greatest challenge to the Registry and the renal community is to use the data presented here to complete the audit cycle and improve patient care. Units are under pressure to improve their performance not only in clinical efficacy but also in cost effectiveness.

The audit cycle is well known (figure 23.1)[1]. Services are planned, partly using the Renal Association standards, the renal units do their best, and the Registry sits at 6 o'clock in checking performance. The difficulty is in acting on the information to bring about change.

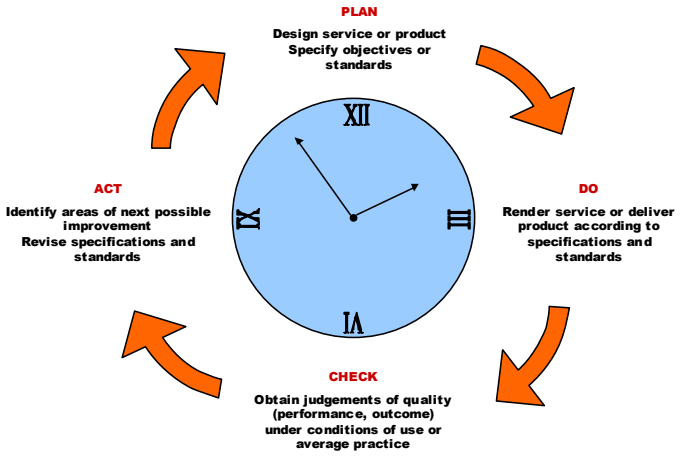


**Figure 23.1 The audit cycle**

The comparison of performance of different renal units is important in preparing the ground for improvement. However the simple observation of differences in performance does not necessarily bring about change, or point the way to achieve it.

The declaration of Standards or Guidelines (at 12 o'clock) by professional official bodies such as the Renal Association, or DOQI, has been an important stimulus to the examination of clinical management. The philosophy of continuous improvement is behind this approach. Recommendations are based on the available literature, which is stronger on efficacy ('can it work?'), than effectiveness ('does it work?'). The costs and safety of complying with these 'official' recommendations are often not considered. The result is that the guidelines thus set are often unrealistic in everyday practice. By an iterative process involving the Registry, Standards/Guideline statements can be validated through the demonstration of current best practice out-turns and distributions.

When the results are inadequate, how is improvement obtained? The usual assumption is that more efficient application of current methods will produce benefit, but that assumes that units

are not trying very hard already. Additional effort without defined changes in procedure may not be effective or sustainable.

## *Insights from Registry activity, and its limitations*

The outcomes of any Renal Unit must be presented as distributions, whether a range over time for an individual, or as the sum of individual measurements. These are the basis for compliance with guideline statements. These distributions are generally stable unless a major effort has been made to influence clinical outcomes. The data are able to confirm improvement or deterioration against a backdrop of random variation. They illustrate the gaps between desirable and achieved outcomes, but do not necessarily indicate the likely cost and effort of bridging them.

In some settings it will be necessary to innovate to improve outcomes. It may not be adequate to rely on individual renal unit ingenuity to achieve this. It will be necessary to devise structures for the implementation of change and exploration of alternatives. The UK Renal Registry runs an annual user's meeting to discuss the data in the annual report. This meeting has pointed up variation in post-haemodialysis blood urea sampling in two separate years, but this has not led to a concerted initiative to standardise the methodology in the absence of an official implementation arm in the audit cycle. The cycle has turned twice without effect. It is well recognised elsewhere that it is necessary to organise specific attempts to improve Unit practice in order to make the most of the QA opportunity offered by registry activity [2,3].

Renal Registry reports have shown that haemoglobin measurements within renal units show gaussian distributions of very similar dispersion (Standard Deviation) (figure 23.2).

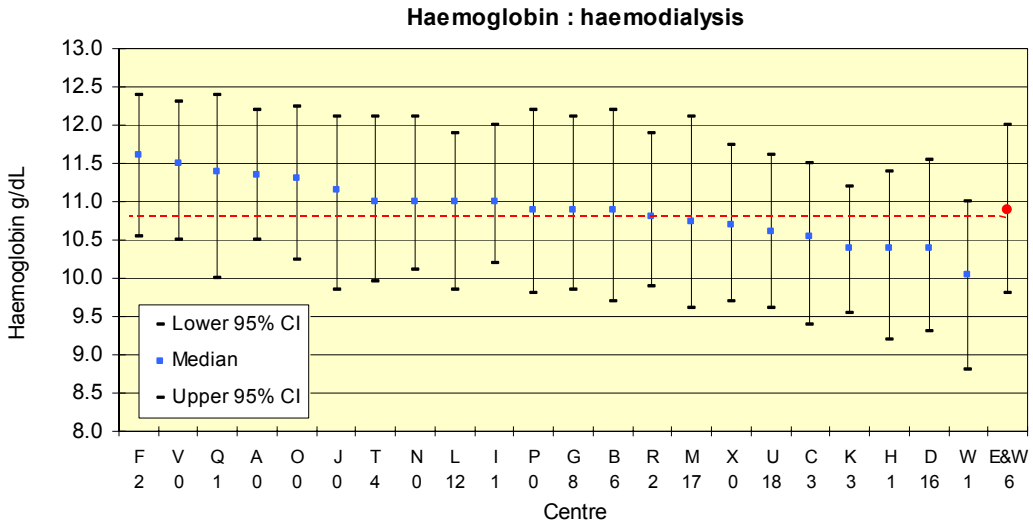


**Figure 23.2 Haemoglobin distributions for UK centres**

There is linear relationship between the median value of the Unit and the percentage above any given minimum value, as illustrated for a minimum of 10,5g/dl in figure 23.3.

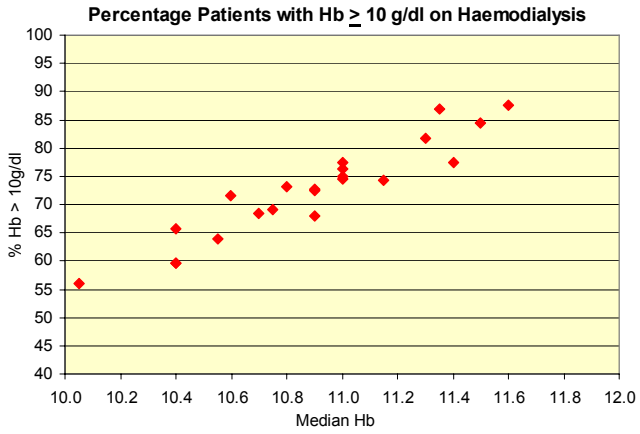


**Figure 23.3 Median Hb against the Percentage ≥ 10g/dl**

Figure 23.3 indicates that with current methods of clinical intervention, to achieve compliance at the RA Standard performance of 85% >10g/dl, a unit will have a median haemoglobin of 11.5g/dl. This degree of 'over-treatment' must be appreciated if the minimum is to be achieved and will need to be justified to funding authorities. Data from the Healthcare Finance Administration (HCFA), derived from completely different populations in the USA show similar behaviour [4,5] (figure 23.4). In October 1998 the average haemoglobin in the USA was 11.1g/dl with 78% of patients achieving a haemoglobin > 10g/dl. This is in keeping with the prediction from the UK data in figure 23.3.

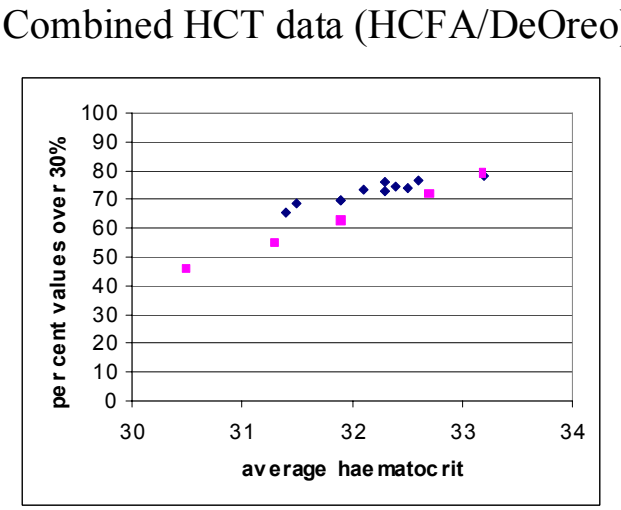


**Figure 23.4 Average population haematocrit plotted against %haematocrit >30 in 2 US studies**

Were it possible to narrow the ranges of data distributions then the curves would differ, but as yet there are no predictable methods of doing so. Adoption of the higher European Standard value for Haemoglobin (11 g/dl)[6] will thus mean a large number of patients will have a very high haemoglobin This approach is important in consideration of the safety and cost of guideline/standard recommendations, since it can indicate likely desirable/achievable outcome

distributions under current clinical conditions, and the implications of them, in advance of attempting them.

## Conclusion

The Registry must fit permanently into the Audit Spiral. To be effective it must retain the permanent interest of clinicians, patients and commissioners. To complete the audit cycle, however, more action is needed. The comparative audit from the Registry is simply the indicator for need to change, but of itself will not bring about change. Implementation of change will be most effective if there is a formalised organisation for implementation developed out of the UK Renal Registry, the users group, Renal Association Standards initiatives, and the Kidney Alliance. Formation of such an organisation should be a very strong platform for improvement in the medium term future of Nephrology in the UK

## References


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*3* Reports from the ESRD Networks. Ed. Jay B. Wish. *Adv Renal Replacement Ther 2000;7(4) Suppl 1:S1-S104*

4 DeOreo PB, Eschbach JW. Implementation of the Anemia Guidelines. *Adv Renal Replace Ther 1999;6:18-27.*

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