

The Renal Registry and a Preliminary Analysis of performance compared with Renal Association Standards

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On behalf of the Renal Registry Subcommittee of the Renal Association

The pilot project of the UK Renal Registry has established computerised links with 6 regional renal units. We present a comparative analysis of a subset of the data for haemoglobin, calcium, bicarbonate, phosphate, albumin, systolic and diastolic BP for peritoneal and haemodialysis in relation to the renal standards. Not all the participating centres were able to supply all the data.

Median Hb for patients on haemodialysis was 9.8 g/dl (8.8-11 interquartile range). The results for patients with an Hb > 10g/dl are summarised below

Centre	% of HD Hb > 10g/dl	% of HD ferritin > 100µmol/l	% of PD Hb > 10g/dl	% of PD ferritin > 100µmol/l
A	48	44	72	52
B	57	66	78	66
C	40	69	59	69
D	38	53	50	53

Further combined analysis of the number of patients with low Hbs and low ferritin in conjunction with EPO usage at each centre is required.

The median [phosphate level for all centres was 2.4 mmol/l (interquartile range 2.3-2.5) demonstrating no significant difference between centres although the cumulative distribution plot is different. The median albumin on PD was 35g/l (interquartile range 32-37).

Centre	% of HD PO ₄ < 1.7mmol/l	% of PD PO ₄ < 1.7mmol/l	% of PD PO ₄ < 1.7mmol/l	% of PD albumin > 35g/l
A	41	42	30	41
B	40	61	50	48
C	21	55	50	45
D	48	68	60	45

This and additional comparative analysis will be available to all centres when they join the Renal registry. Reports will be produced biannually and centre confidentiality be maintained.

Commentary by John Feehally

Since this is the first abstract from Registry there must have been life before the Registry existed, but it is curiously difficult to recall how things were. It is a testament to the success of the UK Renal Registry that it now seems such an integral part of our clinical and research life that it is hard to recall how we made progress without the comparative audit data it now provides on data returned from all adult units and soon, we hope, all paediatric units.

A small start, only 4 units [anonymised of course], and the familiar challenge of incomplete data. And interesting in 1997 to see a range of 38% to 57% between the four units in achieving the Hb target of 10g/dl –in comparison to 85% for HD and 89% for PD in 2008.

We forget at our peril some of the early uncertainties of the Registry and the solutions:

Would anyone but enthusiasts wish to return data? Yes many did, and with the expectation incorporated into the NSF for England that all would contribute 100% of adult centres return from 2008 onwards.

Would financial stability ever be achieved by the Registry? It began to employ staff with grant support and no guaranteed revenue stream, and the sceptics feared the Renal Association's finances might be severely compromised. Instead with the move to capitation, financial security for the Registry has been achieved.

Would we ever move beyond the important but narrow field of renal replacement therapy? Now work has begun to collect from CKD stage 5 not on dialysis, and will soon be followed by data collection in increasing numbers of rare renal diseases.

The authors of this first abstract and many others unnamed who saw the Registry from early uncertainty to its substantial and valued role are owed much by the Renal Association and the entire renal community in the UK.