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P139 -Clinical Registries – a meme?

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The term 'meme' was coined to describe any cultural concept that propagates through Society, rather like a gene (Richard Dawkins 1976).

The aggregation and presentation of clinical activities in a Registry format has become popular in medical specialities. The initial consolidation of data conveys the specialty immediately as a multi-dimensional entity, characterised by the dataset and time-stamped. With the regular addition of material the specialty is seen to develop in time and complexity. As a distillation of the demographic task, the clinical effort and its consequences, it comes to create a 'jewel in the crown' of any clinical speciality. A Registry and its products become a permanent focus for practitioners, communicating across national and intellectual boundaries.

An international element guaranteed importance to the paper-based EDTA Registry from 1965 onwards, in tracking the maturation of renal replacement techniques and growth of national programmes. It presaged modern world-wide comparisons, like IDOPPS. The IT transformation of the 1980s and the 1990s EBM movement permitted an extended intellectual scope to registries, since conventional demographic epidemiology could be combined with measurable aspects of clinical performance.

The UKRR after 1995 was able to rehearse this second maturation of registry development, in URR, Haemoglobin, laboratory variables etc. Special treatment of the data was developed to clarify that experience (Rose-Day). An underpinning by declared treatment standards still sustains the laboratory reporting for comparative audit. In a later EBM step, reporting of infections and vascular access has been explored and achieved.

A third phase of maturation can be discerned in the more recent moves towards multidisciplinary 'quality improvement', focussed on patient outcomes. This is based on the Registry acting as an organising centre, physical and intellectual, for specialty aspirations. The UKRR has been well placed to take up the attempts to generalise best renal practice of the past decade.

These phases have been expressed as principles in Registry Reports but to most will have seemed self-evident. The effort to provide a theoretical background was established by the relationship to the audit cycle, which endures as a deep, if time-worn, rationale. Clinicians have been following the 'Knowing what we do and doing what we should' logic, throughout. In the event, the parochial renal units of the UK are not forged by coherent commercial interests, as in the USA. Renal unit collaboration is voluntary and somewhat incomplete. It is notable that the international comparison chapters of the 1999 to 2009 UKRR reports are not currently being attempted.

It is apparent that Registry functions and influence come from a tacit understanding of certain basic concepts. Over twenty years the products of the UKRR have been modulated according to opportunity, utility and fashionable interests. They have reflected the transients of current NHS priorities and specialty preoccupations. We have been comfortable with speaking of the Renal Registry sequentially as a database, an office, a body of opinion, the base for research projects, a home for speciality interests and the owner of brand-names. That is because it is all of those things, aka a meme.

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P139 -'Doing what comes easily' in Clinical Science?

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Lord Kelvin (1824-1907) famously opined that only measurement and numbers offer secure knowledge in the pursuit of Science. He was not infallible but his advocacy of numbers created a core concept for scientists, including many clinicians. The advent of computing and digitisation has reinforced his emphasis on the numerical, by making data more easily available and displayed.

By contrast, Kelvin also warned of valuing the Abstract more than the Actual. Numbers themselves are a case in point, since we impose them on nature as an abstract version of some real-world context. Barely adequate or incomplete scoring systems are common in Medicine. They become widely employed (e.g. QALYs & 'Stages' of disease) because they offer such useful simplification of untidy realities.

The ready availability of data creates a less apparent hazard, that of diverting attention and research from cognitive and organisational realities. However, non-numerical features are often the means by which data 'signals' can be discriminated from incidental 'noise'. Such an inadvertent 'metrics fixation' is now widely discussed by those concerned with the future of IT.

Is data-rich UK Nephrology, otherwise blessed in clinical IT, vulnerable to important diversions of effort?

1. Data Collection: half the rationale of the UK Renal Registry UKRR

In 1990 Lowrie and Lew described a linear association between relative risk of death and an initial Se [Albumin] in haemodialysis patients. Unsurprisingly, that provoked interest in the possible connection of other laboratory variables to predictable mortality. This was meat and drink to the UKRR after 1995, which to the present day is preoccupied with collecting and presenting laboratory data from UK renal units. This now poorly productive focus permits a diversion from exploring how the results came about (e.g. by promoting more complete unit ESA data reporting). Awareness of the 'What' remains far greater than the 'Why'.

Data Display: the uncertain trajectories of kidney function 'CKD'

The classification of 'CKD' into stages based on eGFR has led to noteworthy anxiety, especially in elderly patients. Often no reassuring prognosis can be made in Primary Care because GP systems were not configured to show trends in eGFR. Inappropriate Hospital OPD review was/is the only recourse, so that serial computer graphics may expose the timeline of renal function. That allows the classification of patients rather than any notional renal disorder.

Data Collection and Display: aids to projecting Acute Kidney Injury AKI

The exposure of AKI through serial Se [Creatinine] and its categorisation into three severities offers a premium for the collection of those lab results and their sophisticated display. That relatively undemanding focus, while central to energising an AKI movement, is in danger of diverting attention from the clinical task, to diagnose and interdict AKI-compounded morbidity and mortality. Extensive contextual data are needed in each clinical case to nourish a useful clinical interpretation.

These examples suggest that nephrology shares the vulnerability to diversions of effort because of the dominant appeal of numerical data. Clearly, the abstractions should not be allowed to frustrate the more demanding exploration of nephrological realities.

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P139 -The four horsemen of the health care IT apocalypse? A heckle from the audience.

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Problem. The digitisation of clinical practice in UK secondary care is progressing. Renal unit-based legacy IT has either to meld with, or be replaced by, Trust systems. These are under development by CIOs, mimicking US dispositions. The US CIO system has dropped most of its clinician advocacy by the adoption of business objectives. US clinicians feel persecuted and demoralised by the relentless demands of digital straitjackets in patient management. This has reached levels of burnout and rejection that need not be rehearsed again in UK practice. However, the monopoly NHS is as unlikely as US corporations to be sympathetic to vocational preferences.

Analogy. What are the characteristics of this scenario, visited on all the professions? While IT benefits are self-evident, the risks are neglected. They can be formulated in the image of Doomsday, since clinicians are the 'poor bloody infantry' of any likely battlefield.

Four Horsemen. In this confrontation the opening tactic is a feigned withdrawal by the First charger, he of IT Temptation. He sports the bunting of short-term improvement in professional performance (safety, uniformity) and the reduction of surprise events. He offers control over the entire clinical landscape on a 'dashboard' BUT for those who break ranks, seeing only benefit, the Second steed storms in from the flank, forcing compliance with Trust business imperatives, the Third nag presses home the barely discussed but inevitable deskilling, and the Fourth rides them down, with red-hot smithy irons to seal professionals inside their self-selected armour of guidelines and pathways. The College relief column is indefinitely delayed. Being locked into IT obliges submission to prescribed core activities, like the pace and content of consultation. The Souls of Practice are readily confined to an IT-defined workspace. This is Faust and we know where that led.

Predicament. Faced with such daunting prospects how should professionals behave? Could the momentum of digitisation be channelled to promote vocational aspirations? The odds are almost entirely against it.

Suggestions. First, acknowledge the come-ons and the inevitable contest. The exposure of benefit-costs will sap the pressures brought to bear, like the arrow showers at Agincourt. Repeated public rehearsal of desirable clinical experience brandishes holistic practice, as clamorously as pounded shields. Minimum consultation times and pruned, flexible, medical record formats are the frieze of pointed stakes that front unarmoured archers. Soft-bodied infantry can secure safer, higher ground through continual, pointed, cautions to CIOs and Medical Directors (who must clarify their CoIs). The ARCH Collaborative audit of clinical IT should be encouraged in every Trust – just what is the price to be paid? The idealisations of IT need to be grounded in more than vanity and the excitement of new technology.

The intangibles of satisfactory professional effort are a handicap when designing its defence. However, anyone can feel the climate of good practice; such indirect measures should be asserted confidently. Clinicians must take (heroic) responsibility for defence of multidisciplinary professional space. If not, they will find their everything being 'rendered unto' an insatiable IT Caesar; the mangled corpse of vocation!