Perspectives on UK clinical renal computing 1979–1994

Seminar at the Royal College of Physicians
19-20 July 2017

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Dr Fergus Caskey (observer)	Dr Peter Rowe
Dr David Dukes	Professor Robert Sells
Professor Francis Dumler	Dr Keith Simpson
Professor Terry Feest	Dr Andy Stein (observer)
Dr Mike Goggin	Mrs Barbara Temple
Mr Mike Gordon	Mr Conrad Venn
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Apologies included:

Dr Afzal Choudhry, Dr Chris Farmer, Prof Tom Golper, Prof Norbert Gretz, Dr Brian Junor, Mr Andy Webb

Participants at the Witness Seminar

From left to right, back row: Professor Francis Dumler, Professor Terry Feest, Dr Nick Hoenich, Mr Conrad Venn, Dr Keith Simpson, Dr David Dukes
Front row: Professor Robert Sells, Dr Mike Goggin, Professor Mike Bone, Mr Mike Gordon, Dr Es Will, Dr Andy Stein, Dr Martin Knapp, Dr Peter Rowe

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INTRODUCTION

Why now?

It is very reasonable to ask of this account of early UK renal clinical computing, why now? The answer lies in a slightly contrived analogy with the classical clinical question of 'why then', which is so often answered in renal medicine by a careful inspection of the co-incidence of time, serial data and events on clinical computer graphics.[1] The longevity of the first generation of IT-enthusiastic renal clinicians, and the laying to rest of their 1980s special interest group, has a notional, current, intercept with the poor grasp that contemporary renal staffs are said to have of their IT predecessors. This is incidentally at a time when the structure of national renal data management is being transformed and the UK Renal Registry (UKRR) is approaching a 25th anniversary.

This edited transcript account of early renal clinical computing speaks for itself, putting flesh on the bones of the 2008 British Computing Society (BCS) report drawn from the literature.[2] This introduction gives the opportunity to indicate the historical context and the salient experiences of those involved. The metaphor of perspectives in the title allowed the reconciliation of both the subjective and objective features of the time.[3]

It would have been better naturally if several colleagues had survived to contribute their perspectives, thinking especially of Mollie McGeown, Hugh de Wardener, and Tony Wing. Remarkably, the participants of the seminar represented most of those active in the 1980s, with the notable absences of Neville Selwood and Sir Netar Mallick. The protagonists did not include clinicians other than consultants, although a renal multidisciplinary team was the assumed backdrop to any discussion of renal unit activities.

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[1] The potential of electronic graphical presentation of clinical data was one of the earliest benefits to be emphasised. Pollack, Buncher and Donovan (1977). For examples see 'Computing and Mathematics in Nephrology.' *Kidney Intl* 1983;24, e.g. Morgan and Will (1983). See also Rayner, Thomas and Milford (2015).

[2] Hayes and Barnett (Eds) (2008).

[3] Ginsburg (2002), p156.

A narrative structure, with attitude

It is natural for even inadvertent pioneers to hope, but also doubt, that their experience will be useful to current enthusiasts. That is despite the inevitable survival of prejudices frozen at the time of retirement and, in this case, being disengaged from clinical IT for a decade or more. The seminar was structured (see Appendix 1) to allow the narrative of early renal clinical IT to emerge but also to expose those elements that might have some modern relevance. Does this past contain any gifts to offer to the present and future?

The British Renal Computing Group (BRCG – 1983–88) brought together the majority of the UK renal computing developments of the 1980s. Its history, deconstructed, offers a comprehensive description of early clinical renal computing activity. That decade of freedom of discovery can be seen with hindsight to have been exploited in three main categories: Computation, data Compilation and Communication (pp 11–21). Computation, as much as the compilation of data, drew opportunistic clinicians to clinical IT, but the other two elements became predominant subsequently. The current early exploration of Machine Learning and Big Data suggests that computation is likely to regain a more equal footing.

The renal context of the 1980s

The UK renal community of the early 80s was a crucible for the innovatory use of IT in clinical, research and planning scenarios. The relatively few clinicians were fully engaged with the demand of burgeoning patient numbers for renal replacement, and the new techniques of Continuous Ambulatory Peritoneal Dialysis (CAPD), satellite haemodialysis and effective immunosuppression for renal transplantation. They were the independent-minded, polymath, agents of more than a decade of renal unit growth and proliferation at the margin of reluctant NHS policy (pp 9–11). Their limited numbers were a form of staffing 'austerity', but their unselfconscious leadership and improvisation was the more effective because of their comprehensive control of the units.[4] They became the informal Clinical Information Officers (CIOs) of their day, without title, sessional space or other acknowledgement. The seminar inevitably does focus on such 'innovators', 'early adopters' and the most IT developed units, as the exemplars of clinical potential. In the parallel IT universe, it was apparent that the very limited capacity of available hardware served to focus and condense computer programs, which arguably refined the capability of the available software; a different form of austerity.

Many features of 1980s renal practice were conducive to the development of clinical computing, as discussed in the transcript. They included the entrepreneurship of confident staff, the incidental scale and nature of the information demands of a 'knowledge-intensive' specialty (the swelling paper records were manifest) and the capacity to raise funds, either through charity or virement of regional renal speciality funds. Remarkably, and not inevitably, highly flexible and comprehensive commercial software became available in the UK to serve the need.

The history and characteristics of the Clinical Computing Ltd development were intertwined with the development of renal unit IT capacities of the 1980s and are explored unapologetically in detail here (pp 22–35 and 89–93). They rested at the start on ramshackle academic foundations, thrived on the idiosyncratic demands of their renal customers, and created the most widespread national clinical computing 'network' in Europe. A near free-for-all of 'innovation' was allowed by a reliable software tool kit, later complemented by the capacity to automate routine outputs from the database.[5]

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[4] Jones, Goodwin and Roberts (1984).

[5] The CCL software was an 'application' *avant la lettre*, intended for development according to local preferences and preoccupations. The 'Quark' (scripting language tool) software enabled the automation (production and timely display) of routine analyses of the database, like activity and exception reports. Together with a configuration editor it enabled the stringing together of enquiries and data transforms to suit the pre-IT modus operandus of each renal unit as well as allowing the development of quite new routines. Denise Barnett wrote 'In the NHS clinicians only had a short period of autonomy over clinical systems.' 'The buzz of improving patient care by achieving mastery over the computer, …. , was taken away from the bedside.' 'For a tiny proportion of health care professions there was a brief period of less than two decades that was computing Camelot.' Hayes and Barnett (Eds) (2008), pp207 and 208.

The graphical potential was exceptionally flexible and capable. The functions were developed by clinical, as much as by computer-literate, staff, who acted by design as creative intermediaries between the computer engineer and clinical possibilities. The idiosyncratic local products of that software facilitation were taken to a margin that ultimately could not be supported or developed commercially, and were part of the reason for a retrenchment to a standardised commercial software product. The cultural pattern was a sort of head over heels. It obeyed none of the formal principles suggested by the BCS for the introduction of IT. It is testimony, perhaps, to the IT suitability of renal medicine that the essentially informal UK network of clinical computing in renal and transplant units survives more than thirty years later, without any central direction or resource apart from an indirect, piecemeal, shaping by the voluntary national renal dataset. That British 'ad hoc-ery', persistently parochial, is discussed in the transcript, together with the eternal concern for complete and accurate data entry. The 'stubbornly' persistent pattern of each unit return to the UKRR, for example the reporting of ESA data, suggests that little change has been considered once local data acquisition routines have been established.

The contested status quo

There are repeated references in the transcript to the unhelpfulness of hospital bureaucrats, local IT departments and civil servants. In the event, there was an empty seat at the seminar table, of those now hidden administrators who at the time facilitated clinical IT development through the approval of funding or the defence of renal unit development strategies. However, the antipathies are typical of the time.

The IT 're-engineering' of unit clinical routines could be frustrated from several directions. While resistance sometimes sharpened the edge of protagonists, certain fundamental elements, such as the generic status of local (departmental) data entry clerks and computer 'managers', could have been managed only with the willing collaboration of the formal NHS, and so was not. Similarly, the purchase, upgrading and replacement of computer systems and peripherals were, and remain, a conundrum, because typically the computing equipment was not added to the hospital's asset base and so existed in an extra-formal limbo.

In fact, the early renal IT experience was also very largely neglected by UK specialist and representative medical bodies, and certainly, later, by the NHS National Programme for IT (NPfIT).[6] It was largely a regional (provincial) exercise, outside the influential metropolitan orbits. Only in the NHS of the new millennium, twenty years later, was significant formal effort put into the clinical IT component of the then unimplemented National Service Framework for Renal Services (to 2010). We should point out that there was no seminar participant to put an historical 'health establishment' point of view.

Rather crucially, the trajectory of NHS IT was determined by the ambition for more generally applicable, hospital-wide, health-related solutions in secondary care.[7,8] The subsequent denigration of 'silo', single speciality, experience was justified in part by the need to reflect the increase of patients with multiple pathologies and the need for multi-disciplinary clinical management expertise in Secondary and Primary Care. However, the self-evident IT suitability of renal medicine was arguably no reason to disregard the progress made by experienced renal clinicians. In Leeds St James's, for example, it was always the renal unit that was requested by academics and the hospital IT department to demonstrate the potential of clinical IT to students or visiting dignitaries. This was at a time when renal units operated often as specialist hospitals within hospitals. They were, in more than clinical IT, 'cuckoos in the (secondary care) nest'.

On the other hand, the consequences of the modern bureaucratic preoccupation with uniformity, safety and accountability were not visited on 1980s clinicians. They were not harassed by the demand for superfluous or contingent data recording; there was no imperative to demonstrate their activity to a notional third party. The initiative was typically vested in the pre-EBM clinician as the

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[6] Cameron (2000), pp22-23. The UK renal clinical computing of the 1980s was not mentioned in this account.

[7] This was not only a UK experience. Vedvik, Tjora and Faxvaag (2009).

[8] Maguire (2007).

agent and arbiter of patient management. For most, there was only a modest sense of needing to submit to what was a clinically-derived IT system.

Special Interest Groups – a natural history?

There were few identifiable controversies in our discussion. (e.g. pp 42–45, 71, 80, 87, 106–109, 112–115) Behind the encounter of embryonic special interest groups with established bodies like the UKTS seems to lurk the myth of Icarus. The apparent benefit of incidental, or imposed, formal affiliation involved an unavoidable risk of interference with vital interests. This was virtual and ultimately unexpressed in the case of the BRCG or actual, as described here during the early days of the UK Renal Registry. Despite such hazards, affiliation would perhaps have bestowed continuity and the chance to mitigate any disadvantages of the sole professional control of a special interest group.

The annual meetings of such groups in the 1980s were designed as today, with expectations of useful exchange and shared experience. The programmes of each annual BRCG meeting (bar 1988) are shown in Appendix 3. Of course, prior to the development of the internet and social media there was little reinforcement of group activity throughout the year. In so far that special interest groups exist largely through the lively exchanges of their members, current IT communications make for stronger identity and immediacy for any modern equivalent. We see that in the frequent, enthusiastic, digital interactions of NHS CIOs on the Internet, for example.

Arguably then, the limited interaction of its members represented an inherent weakness of the BRCG. By 1988 there was little to show for several years of effort in the area of NHS and Specialist formalities (pp 99–102). Other functions, like the co-ordination of digitised EDTA Registry returns, could not be sustained (the paper-based EDTA Registry struggled on until disestablishment in the late 1990s after thirty years). Additionally, by the end of the 1980s, a thorough exploration of topical IT substrates seemed to have run its course. Having a Constitution did not prevent the failure of the BRCG in 1988, which in detail was partly because of exhaustion in the Chairman and perhaps a lack of compensating vigour in the constituency. Doubtless some colleagues lost valued support and contact.

The kidney disease community found other groups to express their IT interests from time to time, such as an annual UKRR meeting. The Renal Association convened subsequently a Renal Informatics Exchange Group (RIXG), chaired after 2004 by John Feehally, when President, although now inactive.[9] A product of that Group, Renal Patient View, provoked a short history of renal IT.[10]

Matters of scale

In the event, the hope for IT coherence that prompted the BRCG was manifest more through multiple CCL installations than any other intervention. The use of mainframe facilities and a variety of computer-facilitated research projects at unit level were superceded by hardware and software development towards desktop technology. However, many of the classical man-machine IT problems were encountered during renal unit-based IT development (p 33). They were approached more easily perhaps because of the very parochial nature of the exercise. Achieving a continuity of trained renal unit staff in all categories was almost certainly less problematic in regional than metropolitan units, as today. In front of the keyboard, CCL database access, using the 3 x 3 number pad, was highly suited to the relatively few (typically thousands), narrow but deep, patient records. The necessary modern preoccupation with cyber-security was not a prominent issue, although there was concern always for the protection of medical records and the BRCG gave attention to the 1984 Data Protection Act. Even so, in some centres an obstetrical history was not always recorded fully, for example.

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[9] https://renal.org/rixg-renal-information-exchange-group (accessed 5 February 2018). Interestingly, the RIXG was not mentioned in the most recent account of the Renal Association, despite being the origin of the very successful Renal Patient View initiative. The RIXG too seemed to exhaust its usefulness in recent times. It seems that even oversight (in the sense of 'responsibility for') does not obviate oversight (in the sense of 'neglect'). Renal Association 2001 – 2010. John Feehally & Christopher G Winearls, online at https://renal.org/wp-content/uploads/2017/06/ra-2000-2010-final-version.pdf (accessed 5 February 2018).

[10] http://historyofnephrology.blogspot.co.uk/2013/01/the-renal-data-revolution-from-1980.html (accessed 10 February 2018).

For a time 'Interoperability' was conferred by the national uniformity of hardware and software, so that the renal IT cottage industry allowed at least the scale of a village infrastructure. A particular advantage was the exchange of records when patients moved between dialysis units or were registered for transplantation at another centre, frequent enough events.

The ideal of clinical profession-specific data entry discussed in the seminar has been taken much further subsequently in the US than in the UK of the 1980s. Unfortunately, the modern social and organisational demands for data, which can only be requited through the clinical record, are being experienced there as a major diversion of clinical effort from patient contact. The imposed scale of data entry is encouraging the widespread employment of 'medical scribes' (notionally, personal, rather than departmental, data entry assistants) for the relief of clinical staff.[11] An early US visitor to the BRCG added his own, moot, historical and career perspective to this modern problem, which has yet to draw much attention in the UK (pp 122–123).[12]

The limited mention of early renal clinical IT in written sources is perhaps partly explained by the skin-tight fit of the IT that was fashioned to clinical activity. That fit was arguably so close that renal clinical IT became normalised as a modus operandus at unit level and as such was unworthy of remark in print. Such an informal normalisation may also be responsible for the absence of any built-in prompts to periodic review of unit IT functionality, a pitfall with continuing consequences for the quality of registry data returns, in particular.

Demonstrations in principle

The exploration in the 1980s of other IT possibilities came to include what became several 'demonstrations in principle'.

Digital modem communication from renal unit databases made UK annual data returns to the otherwise paper-based EDTA Registry possible, on a considerable

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[11] See Hagland (2017).

[12] Armstrong (2017).

scale (in 1987 from 25 UK renal units); this development received no publicity from EDTA itself. The potential of the novel, toe-in–the-water, IT section of the 1986 EDTA annual international meeting petered out in the transition to the first journal publication of their proceedings.[13] UK renal IT development was ill-served by a lack of presentational opportunities; for example, in the programme of ISN's International Congress of Nephrology held in London in 1987.

A properly established, NHS funded, research effort to make the measurement of haemodialysis dose (Urea Kinetic Modelling) a routine function of the CCL databases came to involve the exchange and display of serial Kt/V values from several units. There ensued an incidental collaborative audit of Urea Kinetics, as a model for future multi-unit comparison and prospective study, albeit unpublished (pp 56–59). That exercise preceded the large-scale introduction of audit activity in the 1990s and can be said to have been some three decades ahead of any well-founded UK national studies that depend on the available renal IT infrastructure.

The scale and complexity of unit populations, and frequent transfers of dialysis technique, begged even in the 1980s a convenient numerical expression for planning purposes. As well as the routine reporting of the number of dialysis treatments, several units used their IT to follow the evolution of local practice.[14] Reporting that activity always seemed likely to be useful to hospital managers but the data were almost universally disregarded for years. They simply did not serve the economic and activity models of NHS block financing in secondary care.

Quite the opposite has occurred since the introduction of more focussed financing of NHS speciality services. Even so, it is discussed in the seminar that despite expressing current clinical workloads within the contemporary model of financing, the recruited NHS speciality funds often seem not to reach renal service budgets (p 117).

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[13] Earlier comments in EDTA-ERA Proceedings had exposed the UK lead in renal computing discussed in the seminar (pp 53–55). See also Van Berlo (1985).

[14] Dibble and Will (1984); Response: Hall (1985) (Letters).

As far as the local re-engineering of clinical practice was concerned it is discussed that empirical and evolutionary methods were more typical than conversion on the basis of hard evidence.

In each of these cases the scope of a clinical IT contribution was imagined and enacted well ahead of modern societal and speciality preoccupations. It was only in the early 1990s that Health Services Research became a recognised category of enquiry in the UK.

A gift from the past?

Attempts to find a general description of the consequences of clinical IT were a feature of the early introduction to renal clinical practice, especially since a convincing analysis would have allowed, at least in theory, the development of more effective commercial products. This can be seen as part of the quest for coherent development that first motivated the formation of the BRCG. How far can one summarise the throwing together of man and machine, and what reshaping of activity might have been anticipated?

The meeting ended with a discussion of IT in clinical practice and the balance between the facilitation of clinical tasks and the inevitable demands of an IT system (pp 117–122). It has become clear that the intangibles of practice are threatened by insistent IT systems being inserted into clinical scenarios. The potential for greater safety, effectiveness and efficacy has an experiential price that is difficult to isolate and quantify, and is thus very liable to be neglected and ignored.

As a response to teasing out the consequences of clinical renal IT one participant offered: 'I can attribute a lot of success to CCL but no therapeutic benefit improved as a direct result of your work except that we found life so much easier to work with our patients….'. This impression exposes a thread running through these dated experiences. Clinical activity became somehow easier and this easing had a discernible pattern. The introduction of clinical IT seems to have impelled a shift of clinical practice from largely Reactive positions towards a more planned, even Proactive, clinical stance.[15] This is so consistent that it probably does represent the exposure of a principle, rather than just a set of circumstances.

Other types of intervention can also produce a shift of footing in a clinical service. In renal surgical services, for example, the introduction of Cyclosporine as an effective immunosuppressant in the early 1980s had a profound effect on the day-to-day working atmosphere of renal transplant units. In slowing the features of acute graft rejection and reducing the frequency of the potentially lethal complications of other drugs, the prevailing tone of post-transplant surgical monitoring was transformed. In the Liverpool Unit discussed here the introduction of IT and Cyclosporine were almost simultaneous, which made discrimination of the effect of each impossible. A clearer example is the stilling of unit ambience that typically occurred after the not uncommon transfer from a makeshift haemodialysis provision to purpose-built dialysis facilities.

These phenomena were movements towards a clearer organisation of tasks and the pre-emptive structuring of clinical demand. The clinical IT also provided a sharp reduction in unexpected, unwelcome, laboratory findings. The greater control of the clinical scenario, and many fewer surprises, brought an ease to the rarely defined but readily recognised local 'climate of practice', different for each specialty and circumstance.[16], [17] In clarifying and corroborating what can be

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[15] An identical (parallel) insight, using the same vocabulary, was made in Susskind and Susskind (2015). They do not develop the concept of a climate of practice (*vide infra*), except towards obviously proactive Public Health issues.

[16] The conversion of everyday terms to describe newly described perceptions is irresistible but may be confusing. 'Climate' has been used in relation to organisational culture in the health care literature, with a rather different slant and in a range of contexts (see reference 17). It has been used to describe staff attitudes and beliefs related to patient safety, team working and approaches to the provision of health and palliative care. It has been characterised and scored through questionnaires and scales. By 'climate of practice' I mean the broad pace and mood of the clinical activity and the responsible clinicians. This is quite orthodox given the general use of, for example, 'a climate of fear' (and even the use by Peter Rowe in the seminar). A variety of other terms could be employed as demonstrated in the text: stance, footing, atmosphere, tone, ambience. Such intangible properties seem unlikely to be measurable directly, but staff morale and satisfaction, turnover rates, illness and absenteeism are likely to reflect them indirectly.

[17] MacDavitt, Chou and Stone (2007).

expected when clinical IT is first introduced, the renal experience of the 1980s carries something of a high-level gift to the present. Several participants spoke of pre-IT clinical 'chaos' and/or constant anxiety on the ward, which were relieved through the digital organisation and timely presentation of information.[18] The same experience is repeated today. [19]

Of course, each clinical speciality would be expected to have more or less to gain from the IT transformation because each works in a climate of practice with a different ratio of Reactive/Proactive elements. The renal experience was apparently at the pole of a transformative net benefit towards proactivity.[20] It seems that clinical IT brings the calm of Apollo to quieten the chaotic, reactive hyperactivity of Dionysiac clinical practice.

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[18] The conceivable proportion of human and computer involvement has been examined by Coiera from the point of view of creating information systems. Coiera (2015), diagrammatically fig 2.5 p19, fig 9.3 p122.

[19] For example: comments reported by Laura Stevens from Addenbrookes' Senior Nurse Charlotte Foster: 'It does seem, however, that staff have gone on a journey to become Epic converts. Foster admits it was "daunting" prior to the go-live as "everyone was very anxious about how it would work". But she too wouldn't go back. She tells me handovers are better, documents can more easily be kept track of, and contending with clinicians' illegible handwriting is a thing of the past. "[It's] just made everything a bit tighter and a bit safer, and made us a bit more organised. I wouldn't go back"'. Stevens L. Three years on from Cambridge's Epic big bang go-live, *Digital Health*, 23 August 2017' https://digitalhealth.net/2017/08/three-years-on-cambridge-epic/ (accessed 5 February 2018).

[20] This formulation owes much to the longstanding interest of Mike Gordon in wishing to fully understand the effort in which he and his colleagues felt engaged; that was, passing over much of the clinical IT development to interested local clinicians rather than trying to digitise suggested routines by outsourcing to IT professionals*. The idea of a characteristic specialty ratio of Reactive:Proactive demand was his. This would seem to allow a more coherent matching of the cost:benefit of the introduction of clinical IT to the wide range of specialty activities in secondary care. Such a ratio will be largely notional rather than numerical, except at some obvious margins like A&E (>>1) or Psychotherapy (<<1).

*The debate about this continues, not just in terms of the process of the clinical to software translation, well demonstrated by two comments posted online on *Digital Health.net* https://www.digitalhealth.net/2017/08/three-years-on-cambridge-epic/ (accessed 6 May 2018):

Sudheendra Kumar (30 AUGUST 2017 @ 00:25) 'This is where the Core and non Core aspects of a hospital come into picture, in my opinion, IT Organization for a hospital is a part of its non core services, this can probably be Outsourced to Managed service firms who can keeps the IT lights on for Health Systems. From a hospital standpoint they need to set up a Liason in the form of Medical Informaticists who can understand the needs of the hospital and get them translated into requirements and get it delivered from these managed services firms.'

DistinctlyRandom (5 SEPTEMBER 2017 @ 11:23) 'Outsourcing… has anyone *not* found that this overtly diminishes quality? I'm not just talking about IT but it applies here too. I've seen it throughout the NHS. It is extremely difficult for one organisation to hold another accountable for something as subjective as the quality of their work and, without a vested interest, why would any third-party that purely provides a service, choose to devote their resources toward reproducing in-house quality rather than just ticking the functional delivery?'

Is this observation of any current relevance? Does transformation by clinical IT actually vary according to clinical specialty? Practitioners, by instinct and exhaustive training, like the military, have achieved the capacity to react comfortably and competently to unheralded clinical (reactive) demands. They achieve a positive personal feedback (of a nature described by Aristotle) from the rewarding rehearsal of hard-won expertise.[21] Trainees are observed to be stimulated by the confident, effective, management of unstructured clinical scenarios. This investment is jeopardised by imposed digital templates and data recording disciplines, quite apart from the little-discussed slippery slopes of deskilling. By contrast, participants spoke of the attraction of digitised information flows to contemporary trainees.

Just as retirees may be loath to regard themselves as defunct, specialist practitioners who have honed their capacities in a less organised clinical world cannot be expected to welcome without reservation their exposure to the consequences of the introduction of clinical IT. It can come to represent yet another unmitigated bereavement of their career experience. Such an insight deepens an appreciation of the submission to IT for 'luddite' clinicians and offers a quite specific existential counterweight to the hyper-rationality of the 21st century. The offer of access to clinical IT, with the promise of healthcare awareness and control, is being made increasingly to patients and may deserve similar caveats. The development of Renal Patient View from unit databases has been an early and effective example.

The ageing retirees of the seminar, on the rising, exponential, frequency curve of personal physical breakdown, probably sense the advantages of patient IT access more keenly than clinicians of working age, so let us hope that the benefits continue to outweigh any unintended consequences.

An unusual chance to eavesdrop on an earlier professional world

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[21] As a clinical experience of 'eudaimonia'? (Aristotle in 'Nicomachean Ethics') or a realised potential of the personality? (Entelechy).

This introduction will do a disservice to the seminar if it does not wet an appetite for the transcript itself. It is simply not possible to express the quality of the exchanges in summary and it is to be hoped that this account of an enjoyable reunion will inform, stimulate and amuse its audience as much as it did the participants. Goethe would have understood their experience.[22]

Acknowledgements

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Other multitudinous thanks are due to Adam Wilkinson, Professor Tilli Tansey, Debra Gee, Caroline Overy, and our observers Drs Fergus Caskey and Andy Stein.

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[22] 'History writing is a way of getting rid of the past'; 'he is the happiest man who can set the end of his life in connection with the beginning' *The Maxims and Reflections of Goethe*. Second edition. Macmillan & Co 1908.
https://archive.org/stream/maximsreflection00goetuoft/maximsreflection00goetuoft_djvu.txt (accessed 19 February 2018).

Perspectives on UK clinical renal computing 1979–1994

Dr Es Will: Welcome to everybody to this meeting, which is designed around the British Renal Computing Group (BRCG), and to some extent must inevitably represent the swansong of that group.[1] We have put together a programme that tries to put the group in the context of the NHS in the 1980s, in particular, and the intention is to move from the introduction of particularly minicomputers in renal practice, across that decade and into the early part of the next decade. The BRCG operated between 1983 and 1988 essentially and that's the period that will be the point of greatest focus.

Because the NHS has changed so very much in all of its attributes, we thought it was useful to include some kind of introduction to the clinical context, particularly the predicament of senior clinical staff in the NHS of the 1980s, and we'd like to kick that off with a discussion, which inevitably will be partly based on centre experience but which has some general features. So, if Mike Bone would start us off, that would be great.

Professor Mike Bone: Thank you very much indeed, Es.

I now understand that Renal Services were (as were Cardiac Services) a special responsibility of, and funded directly through, Regional Health Authorities. The situation of the NHS in 1975–79, was that Regional Health Authorities passed responsibility (and funds) to Area or Sector Health Authorities, thence to District Health Authorities, who supervised Hospitals, General Practice, etc.[2] The inter-relationship with all of these various bodies was often described in diagrams of boxes with arrows going backwards, forwards, sideways, linking 'here', swooping round to point to 'there'. It reminded me of one of the teaching slides I used relating calcium and phosphorus to Vitamin D metabolism, the kidneys and the

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[1] See Appendix 1 for the structure of the seminar.

[2] 'The organisation of medical work in hospitals' 1967 http://www.nhshistory.net/cogwheel.doc, (accessed 17 January 2018).

parathyroid glands, which could easily be replicated in terms of the structure of the NHS.

My appointment as a Consultant in 1975, in Liverpool, was made by the Area Health Authority, but working in two different Hospitals, one a Teaching Hospital, the other a District General Hospital. There was a Sector Administrator and a Branch Medical Board for the Consultants. It was all potentially confusing. My own contract had two sessions for teaching and research, as had most others, I think. This new post was in part to help Robert Sells, who had been in Liverpool for some four years. My remit was to look after the medical/renal side of Renal Transplant patients.

But what was a consultant for, and how had I been prepared for this? Well, the main thing was it was taking clinical responsibility at the highest level, as an independent practitioner. This was where the buck stopped. And it did remind me, that 'you just have to make it up as you go along'. Well, this is something which we all of us do all the time because every patient is different; it's always a new situation.

But, as Robert rapidly showed me, the main problem lay in preparing patients for surgery, and while this might not appear to have anything to do with Information Technology, its solution, as you will soon see, had a surprisingly big impact on the development of the Transplant/Renal Unit computer in Liverpool! It was rapidly clear that there was no money to cover the effects of my appointment, to let me do my job properly. Well, we weren't taught anything about money at medical school, either.

We were aware of a hierarchy within the consultant body, represented traditionally by the number of beds consultants 'needed' to put their patients in (however, my time in the USA showed that this was not the only way). As a Consultant I soon became aware of committees, but then my own experience with committees was very limited at medical school because I spent most of my spare time either climbing mountains or other related 'social' activities. We also became aware of surgeons being different from physicians: surgeons had knives in their hands, rapidly diagnosing and conclusively treating; physicians sort of mulled things over, they swithered and couldn't make up their minds. This wasn't only in London. The Edinburgh Royal Infirmary had a Medical Corridor down the hill from Lauriston Place, with 10 Wards branching off for the physicians. Further up the hill, closer to the road (and Casualty), was the Surgical Corridor with ten Wards for the surgeons. And obviously the theatres were there, with the intensive care unit close by. The physical differences matched the apparent remit.

In terms of the kidney treatment, there was dialysis, with limitations, and there was transplantation. There was also 'conservative' management with, in those days, low protein diets, as well as blood pressure control, which was quite a struggle itself. We were concerned about acid-base balance, certainly in Edinburgh. Sodium balance was easier to control, since we were now getting strong diuretics such as frusemide. But we were not touching then either the anaemia or renal bone disease that patients had, the latter a very complex situation relating to the lack of active Vitamin D metabolites, the most effective being made in the kidney. More to the point, in Liverpool 'deserving' patients were being referred for transplant surgery with no prior dialysis. Robert's results over the first three years showed the considerable risks with this approach: graft survival after one year was only 25 percent (vs. 50 percent for patients treated on home haemodialysis). Mortality was higher, too: one in four patients died after being transplanted from conservative support alone (vs. one in ten from home haemodialysis). Even worse, 25 out of 26 'diet only' patients died before a kidney could be found. This was more of a 'death list', than a waiting list for treatment. I am sure Robert will have his own blood-curdling tales to tell later.

Funding eventually (1978) came from a 'Small Grant' from the Department of Health and Social Security (DHSS) to establish a small, 'Self-Care' haemodialysis facility separate from the main Dialysis Unit, and two miles away, specifically for patients awaiting transplantation. Funding included a Renal Research Fellow, Dr Geoffrey Taylor, who had been my Renal SHO, and who was keen on computers. He had even built his own colour TV set. His appointment was two years ahead of the arrival of the Transplant/Renal Unit Computer, in 1980, but he still had nearly two years after that before he moved on, and his contribution to our exercise cannot be under-estimated. So insofar as history is about people, my reflections will rely on my own experience and one of the nice things that we learnt from CCL (Clinical Computing Ltd) was this word 'timeline'. My timeline takes off from 1965, when I started renal medicine as a Carnegie Research Scholar at the Edinburgh Royal Infirmary where I earned little more than as a House Officer, and which was why I gave lectures in post-graduate courses, including one attended by Mike Goggin here. From there I spent nearly two years as Instructor at the Jewish Hospital in St Louis, Missouri, which was very educational in a variety of different ways. I was left healthily suspicious of anything imported from the USA, such as the widespread, (and in my view) poorly questioned blanket use of 'eGFR' (Estimated Glomerular Filtration Rate), and 'earlier' dialysis, both happening after my retirement in 2005.[3]

Will: Mike, can I ask, I would like to extend that point about being abroad because it was a very common cultural experience for nephrologists to have gone to particularly the US to get experience, some of it was clinical, a lot of it was research. There was a tradition that nephrology was a semi-academic topic. People expected themselves to do research and they expected to take a detailed interest in their nephrological surroundings. Martin Knapp, for example, was one person who did a similar sort of trip, in his case more than once. People coming back from those attachments obviously had a different perspective on what they were doing and were differently enabled in what they were doing. The reason I think this was important was that after the Ministry of Health discussions of the late 1960s, my understanding is, some money for maintenance renal failure treatment was put out to the Regional Health Authorities and consultant

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[3] Professor Mike Bone added: 'The developments relating to our Computer are given in Figure 8 on page 65. It has to be said, however, that not every Consultant on the Unit was altogether familiar with what was available, as shown by the exchange in 2003, when I had described our progress over the previous 23 years, at a lunch-time Unit meeting: Un-named Transplant Surgeon: "Why can't we have biochemistries (esp. LFTs) from as early before transplantation as possible, like when patients are first referred to the nephrologists?" Answer (Mike Bone): "You have been getting just this, and a lot more, since your appointment, 14 years ago!"' Note on draft transcript, 4 April 2018.

nephrologists were appointed as regional resources. They were told essentially in many of the major centres, typically academic, to set up maintenance haemodialysis units, and they were given a lot of scope to do that.

They did that task essentially as renaissance men, with gusto. With hindsight it was one of the features of adopting IT early, because that was the way that people expected to operate, to take advantage of their environment and to do what they could within it. And there was, as you hinted, a lot of improvisation.[4] There's one story that has stuck with me from David Dukes, who is here, about his improvisation in Coventry, and David, perhaps you could give us a narrative?

Dr David Dukes: Mike's comment about 'making it up as you go along', rings bells with me because I had been a Lecturer in Medicine at Harare, in what was then Rhodesia, and came back from four years of a bit of experience of dialysis, acute dialysis, in that country and my wife was training to be a surgeon and she had got some good experience of creating access. So when I was appointed in Coventry as general physician with interest in nephrology, the curious comment after the description of my job was: 'that it is expected that all dialysis on Coventry patients will be undertaken in East Birmingham Hospital (which is Heart of England Hospital now).' I thought this was rather strange but nevertheless we pressed on. Six weeks after I was appointed and started working in what was then the brand-new hospital at Walsgrave in Coventry, I was asked to see a patient with acute renal failure by one of the cardiothoracic surgeons, Bill Williams, and, of course, the patient was then too ill to be moved. She was being ventilated and on various other life support systems that existed at that time. Fortunately, an old friend of mine, Brian Robinson, had been appointed at East Birmingham Hospital, at the Renal Unit there.

I was able to ring him up and say: 'Please can I borrow a machine?' He sent over a Lucas Mark 1, which was kindly plumbed in for me to the side ward by the

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[4] Dr Eric Will added: 'This was especially true in the 1970s in places where dialysis had not been formally established by Regional Health Authorities (*vide infra*).' Note on draft transcript, 9 January 2018.

cardiothoracic technician, Fred Roberts. And Heather, my wife, established access. We started the patient on dialysis and all was going well until a very anxious looking administrator came in and started pasting brown paper over the windows into the corridor to conceal what was going on inside, [laughter] because it just so happened that the Minister of Health was visiting the hospital to make sure that all was well before it was formally opened by the Queen. He was led past our room and said: 'What's going on inside there?' And he was told: 'Oh, we're using it as a store room, sir.' [Laughter] This is how dialysis started in the very, very much 'make it up as you go along' situation in Coventry. Then of course several other patients with acute renal failure followed and they did well. Within a few weeks another old friend of mine, Tony Barnes, a fellow student who'd set up the Transplant Unit at Queen Elizabeth Hospital in Birmingham, rang up to say he'd accepted a patient for transplantation but there was no room in the renal units in Birmingham to take her, would I take her? I said: 'Yes, of course, Tony, but we'll need another machine.'

So they lent another machine and the patient was started on haemodialysis to await transplantation. This was the embryo of the Renal Unit in Coventry. Once started it couldn't be stopped.

Will: By using the name of the technician and acquaintances, you indicate that these were cottage industry type developments?

Dukes: Oh very much so, yes.

Will: The initiative being the clinicians'?

Dukes: It was sort of a personal arrangement, person to person. But I have to say we got very good support from the Regional Health Authority, which of course was essential from the financial point of view. Interestingly the finance came along. We had tremendous support from them and also from the sub-committee of my colleagues, who were working at other renal units in the Midlands and who gave us their blessing.

Will: So Mike Goggin, you were in the same sort of environment?

Dr Mike Goggin: Yes, but really what I want to say is how dialysis in a sense came to me as part of my clinical training pathway. Instead of going to America and doing all these things, I started off my clinical career as a general practitioner. I was in general practice for 4¼ years so I had quite a bit of catching up to do. As we all did, I went through many specialties, so that we got lots of experience in different things, and the one before I came into renal medicine was at Harefield in cardiology. Now the interesting thing in the history of that is there were a lot of thoracic surgeons who were brought up in treating tuberculosis, and the antibiotics and other measures had got rid of tuberculosis and there was nothing for them to do. So they all aspired to be cardiac surgeons but they were very slow, and people were on the (by-pass) pump for a long time, and so there was probably a higher incidence in those days of (post-operative) acute renal failure in Harefield. We didn't have a dialysis machine ourselves, but a very fortunate situation existed in that Joe Joekes lived in Uxbridge. Joe Joekes was a well-known renal physician, and he was the civilian consultant to the RAF. So the natural thing to happen for dialysis to come to Harefield was for it to be brought by the team who travelled all around the world to dialyse people from the RAF. That's, in fact, how I came into renal medicine and obviously, as the pathway was, I became very useful in this situation and I got hints that perhaps I should go into nephrology and as an introduction into what jobs might become available, I joined Joe Joekes at Covent Garden at the famous hospital called The Three P's, St Peter's, Paul's and Phillip's.

Will: Martin, you had a lot of experience of setting up too, didn't you?

Dr Martin Knapp: In 1967 I was a Senior Registrar and Lecturer (in Medicine) in Bristol. We knew there was dialysis happening around the place in tertiary units with prestigious people setting up units. In Bristol we also had a small unit for acute renal failure in the Infectious Disease Hospital at Ham Green. The professor tapped me on the shoulder and said: 'Martin, we'll start dialysis here at the Bristol

Royal Infirmary and you'll start it.' He didn't offer me tenure but he did tell me what to do. We went up to Newcastle and discussed the strategy with Professor David Kerr and I was advised to use a Kolff machine because it was simple for a beginner. I went and did a crash course in Glasgow for a week, and then I came back and unpacked the box. With the help of a recently appointed registrar from Sheffield, Margaret Horne, who had had some experience, we ran a unit there with a handful of patients until there was a Transplant Unit started in Southmead Hospital. Southmead took over the whole show and ended up with the history you all know with Bristol becoming a very prestigious centre with prestigious people, one of whom is here today.

I went over to the States for a second time and worked with Neal Bricker in St Louis where I was Co-director of the Chromalloy Dialysis Unit at Barnes Hospital. I came back to a General Physician appointment in 1970 and started at Nottingham, where again we had a similar situation to Bristol in 1967, with zero activity across the whole board. Only three people from Nottingham had started dialysis in the previous year. We did a survey and found there were 50/year presenting and thrust this into the hands of the relevant managers who were really very supportive at the local level, but for three years nothing happened in terms of funding.[5]

We initially had one machine running, which had been donated by a charity. We eventually presented a list of patients who needed maintenance treatment and asked the Regional Authority which of them we should let die. We never got a reply but we did get money and from then on became relatively well funded. We were joined by Roger Blamey and established a renal transplantation programme and continued the donor kidney retrieval service which I had set up.[6]

Will: This initiative/improvisation business is in such a contrast to today. In particular, people today have an interest in promoting 'leadership' but of course

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[5] Dombey, Sagar and Knapp (1975).

[6] Dr Martin Knapp added: 'and we increased our uptake of patients onto the Nottingham end-stage renal failure programme to be one of the most effective in the country despite minimal staffing, generating a need for effective IT.' Note on draft transcript, 5 October 2017.

the things we're describing were leadership in action that didn't have a name; it was actually people taking the initiative and improvising, with some hindrances, and we shouldn't say that people weren't constrained financially and bureaucratically. Actually, they had been given the nod to develop the facilities in whatever way they could. Every place was slightly different – everyone started from slightly different set of local capital assets, as it were, social and otherwise, and then developed them. The initiative was meant to be with the clinician. Terry, you've got some stories probably from that?

Professor Terry Feest: Well, I think it was more chaotic than that. I would take up what David said, a lot of people were not given the nod, and a lot of people were not appointed to run dialysis. So where I trained, you know I did most of my dialysis training in Newcastle with David Kerr, who had been appointed originally as a hepatologist. I worked in UCH and they surreptitiously got dialysis machines into the hospital where they weren't supposed to. I worked in Exeter, where it had been started by Harry Hall who was a gastroenterologist with no renal training, he'd not been given a commission to start dialysis, he started it because he saw a need despite what the management said. That was your experience; you weren't appointed to run dialysis, you were appointed actually not to run it! And I think some of the people who were appointed were appointed as gatekeepers as well. So I don't think it was an orderly Health Authority saying: 'We need to appoint someone for dialysis.' A large number of units started up with the opposition of the authorities because people saw the need. And we had to battle like hell to get any resource or recognition.

Knapp: Okay, I was going to go one step further in that direction. It wasn't easy. We actually had questions in both Houses of Parliament between 1973 and 1975.[7] It was only really when the lack of facilities became apparent to them that the MPs started to become involved. We had front page coverage in the press about lack of money, lack of dialysis, need for donors. MPs asked us to come along and feed them

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[7] For example, questions in the Commons by James Lester to the Minister of State for Health and Social Security, David Owen, on dialysis treatment in Nottingham, 31 July 1974, http://hansard.millbanksystems.com/written_answers/1974/jul/31/dialysis-treatment-nottingham#S5CV0878P0_19740731_CWA_1103 (accessed 22 February 2017).

information, and to construct questions that they would then ask in the House in order to embarrass the other side. Since the other side knew the answers it was embarrassing for them but effective in the end. We also wrote about it in the *BMJ*.[8]

Will: I don't want to rehearse the history of UK maintenance dialysis in detail![9] My understanding is at the end of the 1960s that people realised that this was going to have to happen somehow. The Hepatitis B of the late 1960s /early 1970s didn't stop it in the event, although there were some thoughts that it might, and the regions were given money to set up dialysis, maintenance dialysis facilities. There was a phase when a case had to be made in all sorts of different ways for subsequent funding, in a very hybrid and heterodox (even inadvertent) model. But the point I was trying really to make from this, which I thought would be interesting, was the notion that clinical initiative, improvisation, and leadership was possible, manifest and even strongly desirable, but particularly in the renal area, and that was one of the many things that was behind the development of the renal IT. Without that context a lot of what we might go on to talk about might not have occurred.

Professor Robert Sells: Chaos in dialysis affected transplantation of course, and I thought it might be interesting just to say how the Liverpool group started. There was early success at St Mary's and Edinburgh and the Hammersmith. Roy Calne was pioneering kidney and liver transplantation in Cambridge in 1965–66. In Liverpool a group of local consultant physicians and surgeons, one of whom was a nephrologist, and three urologists plus a vascular surgeon from another hospital, got together as a group to inaugurate renal transplantation in Merseyside. The first three patients died, and the second three lost their kidneys within about three or four days, at which point the Chairman of the United Liverpool Hospital stepped

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[8] Dombey, Sagar and Knapp (1975).

[9] The 1960s equivocation of the Ministry of Health over the provision of maintenance haemodialysis has been discussed elsewhere, for example by Professor de Wardener. http://cybernephrology.ualberta.ca/ISN/VLP/Trans/deWardener.htm (accessed 30 January 2018). Also Crowther, Reynolds and Tansey (Eds) (2009) p47. The first new centre of the NHS regional programme was at Leeds, St James's, developed after the appointment of Dr Stanley Rosen in 1966. Several dozen other centres in academic settings followed, complementing those facilities that had been started piecemeal by entrepreneurial clinicians (Royal Free, Newcastle, Charing Cross, Liverpool etc).

in and said: ‘No more transplants, we’re going to have to advertise.’ Professor Bob Shields, who was a gastroenterologist, but with a very broad view, had a ‘frozen’ Senior Lectureship which he decided to use to attract a Foundation Director of a regional transplant unit, for which resources had been approved by the Department. I was working with Roy Calne when I happened to go and give a lecture in Liverpool just before I departed for my BTA (Been to America) at Harvard. That was the link which eventually brought me back to Liverpool where I was appointed Director in January 1971.

Will: So both in transplantation and haemodialysis at the time there was this kind of curious stuttering start. People had to take the initiative and force, each in a different local context, what was going on. But the atmosphere after the source of the prompt in the NHS was still, in that sense, pro the initiative of clinicians; it wasn’t something that people didn’t expect to do at all. It was something that they did expect and as we were hinting, may have been encouraged in some instances to do.

I think we should move on directly into the IT, and one of the things that struck me about reviewing this is how very strong the incentive of computation itself was a prime mover to interest people in the development. So these days, with one or two exceptions, we’re mostly interested in the information management element of clinical computing with all its various attributes, but computation, the purely computational aspect, the mathematical aspect, is much less obvious, certainly to most clinicians. And that may be fine, but in fact a number of people here came at the IT particularly for its computational potential. I would say that was easily equal to, if not greater than, the issues of managing the clinical data, although very often of course it was a hybrid development. So Mike, you in particular took on some of these computational possibilities across a range of activities in the Canterbury Unit, which were not directly related to patient records. Is that a fair comment?

Goggin: That’s correct. They were one off situations. I think one of the interesting things was that somehow I came across a research fellow who was nothing to do with medicine, who was a mathematician, and he produced quite a lot of things for us that needed mathematics. I think the first introduction to it really came from a project that was run by a University of Kent student which was to do with drug interactions, under the name of ADICT, which was Archiving Drug Interaction by Computer Terminal. But that's by the way. We worked closely with the University at that time and collaboratively developed a simulator to teach dialysis to patients who were destined to go home.

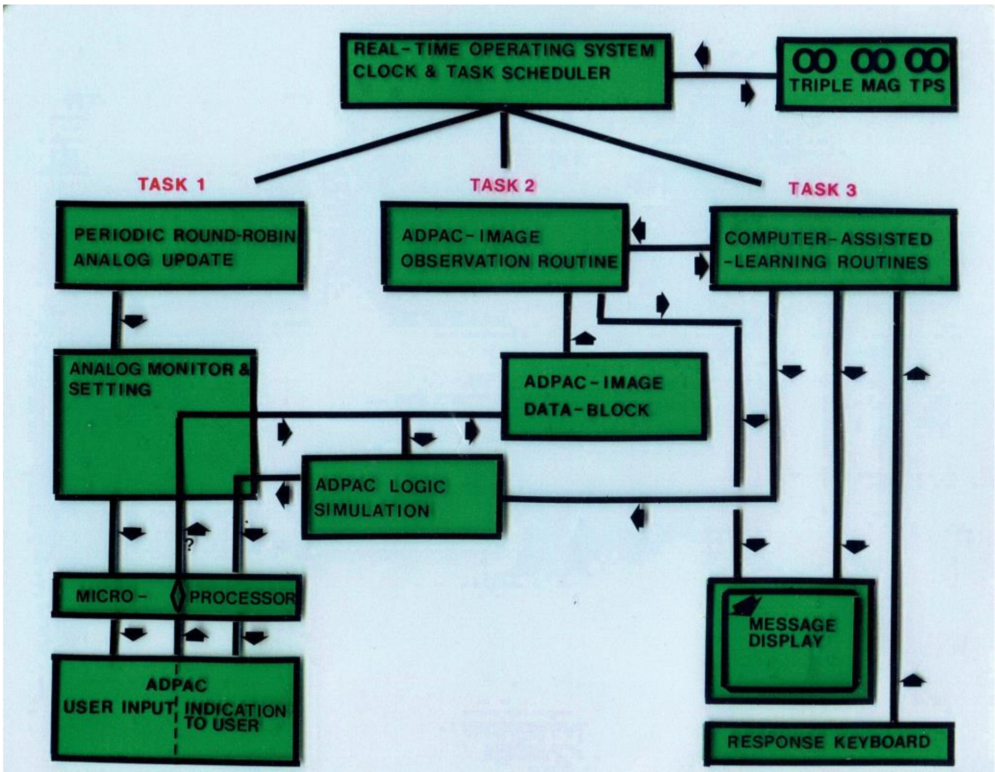

Figure 1: The flow diagram dialysis training simulator

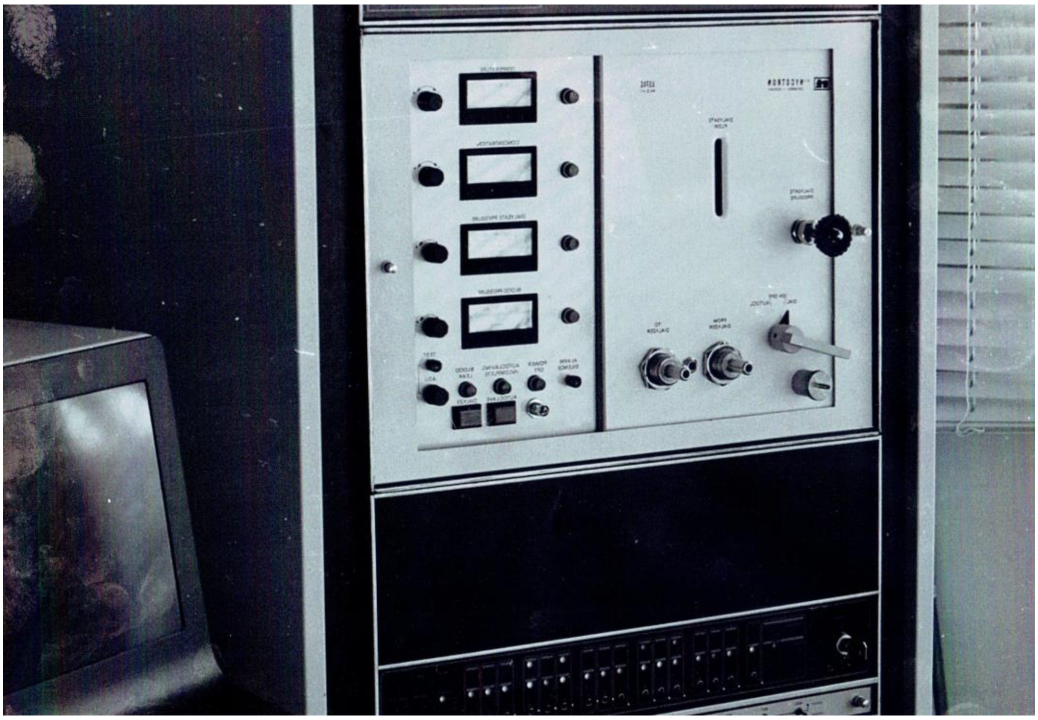

Figure 2: The hardware for the simulator, showing the computer terminal and the Nycotron ADPAC dialysis machine front panel, embedded in a Data General Nova computer

But when the mathematician came, one of the things that he didn't like was the way that management constrained you from doing things, even in those days, especially if you tried to go big. So he went small and ended up by writing a lot of programs that were on an HP97 programmable calculator.

Figure 3: A Hewlett Packard 97 programmable calculator with input magnetic strips and LED and printable output

Among these things, we did urea kinetic modelling (UKM). We also did things to do with what we were interested in, for example nutrition and malnutrition so we did things in relation to that; things in relation to (renal) stone risk, which were based on work that came out of the Leeds MRC (Medical Research Council) Unit.[10]

We did eventually put the work on to a minicomputer, having been through a number of problems trying to use other people's computers, particularly we had a link with the University. But the constraint was that telephone lines were unreliable. We used modems at both ends and these were slow and also unreliable. We were driven in the end to use an IBM (International Business Machines) card punch. So all the data was typed in on an IBM card punch, it was put into metal boxes, we took it up the hill to the University, it went through their card punch

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[10] Dr Mike Goggin added: 'Eventually because of the unwieldy nature of renal patients' notes in the early 1990s we developed a system of problem oriented medical records which were slotted into the hospital patient administration system. Many of these initiatives were driven by the need for information to be available on multiple sites in the hospital and the ever-increasing satellite haemodialysis units.' Note on draft transcript, 10 October 2017. See Weed (1968 and 1971).

reader and the next day we'd call for the output, which gave us the graphs from what happened in dialysis.

Will: So this was a mainframe liaison?

Goggin: A mainframe at the University.

Will: Nick, I know that you had a lot of experience latterly about the mainframe interaction with healthcare, but your experience was generally a little negative in terms of support.

Dr Nick Hoenich: I think it was very difficult in the early days. There was clearly an interest in what to do with the mass of data that was being generated by dialysis patients. David Kerr, at Newcastle upon Tyne was instrumental in developing links with the Regional Health Authority who had a mainframe computer that was used for payroll and other applications. Two temporary input personnel were appointed to input the data onto the Regional mainframe, with a view to subsequent analysis, only to discover that the data was was in the specific format for whatever computer the Regional Health Authority used, and it was impossible to read the data on another computer and to undertake further analysis.

I think Terry used the University Computing Service for some of his activities when he was in Newcastle and having worked on the other side, so to speak, in the University, I too had used the University mainframe computing system, however it was very difficult to try and convince people to think of using the mainframe outside of the physical sciences and the mathematical analytical part that they were so used to. There was no expertise within the University Computing Department of what you would call healthcare computing.[11] The department was concerned primarily with data generated by clinical trials, whereas the University Computing Department were concerned with analysis of data generated from

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[11] Dr Nicholas Hoenich added: 'although there was an active medical statistics department headed up by Professor David Newell (1929-2016). (Obituary in *Statistics in Society* Series A, 6 January 2017; 180: 348–350). Note on draft transcript, 4 November 2017.

experimental studies in physics and engineering. If given a set of data on x-ray diffraction they would be able to plot out where the molecules were because that's what they did, and they did it very well, and they did it very quickly. Give them something else outside their normal remit (data fitting) it was slightly more problematic for two reasons: first there may not have been expertise available, and second you needed to have some clear idea as to what you wanted to do with the data that you have generated. This was relatively simple when dealing with scientific or engineering topics as for many the interest lay in the limits or boundaries of the solution of the mathematics. It was more difficult in the context of healthcare, particularly as often records for the routine treatments were missing information or were lost. The situation changed with the introduction of the CCL system which post-dated these early attempts and allowed retrospective analysis of large amounts of data, provided that the data did not have substantial elements missing.

Will: So there were not only technical difficulties in getting the material in and transferred and then out again, but there were some cultural blockages at the time about who was going to operate the system and how and with what?

Hoenich: Yes. An additional problem was that there was no clear idea as to what to do with the large volumes of data that dialysis patients accumulated. Retrospective analyses were of interest, but lacked any predictive element.

Will: So it was mathematically exploratory but not culturally exploratory, if you see what I mean?

Hoenich: Yes.[12]

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[12] Dr Nicholas Hoenich added: 'One unexplored element following the availability of the CCL system was that for the first time, renal units had to work with a commercial entity which may have had an impact on the evolution of the specialty.' Note on draft transcript, 4 November 2017.

Will: Martin, you wanted to solve some quite refined, predictive mathematics and got involved in this with mathematicians of course, but that was one of the prompts for your interest in the IT?

Knapp: Yes, well we were initially doing research using mainframe computing to analyse sequences of laboratory results, and using computers as a tool for more complex analysis after we got this very busy unit going in Nottingham, and after we had started transplantation. We were initially trying to do epidemiological predictions – predictions of need in order to make the case for more money, more staff, and the other things that you are all familiar with. A paper came out in 1976, from Mitch and Walser in *The Lancet*, which pointed out that if you converted the (Serum) Creatinine to the reciprocal you actually changed a hyperbolic curve of progression into a straight line, which was extrapolated effectively to become the time when dialysis would be needed, if you were looking at chronic renal failure data at the time.[13] We also applied that technique to patients after transplantation and found it was easier to follow the post-transplant course, when rejection was the crisis we needed to know about and treat quickly. I started drawing graphs on specialised graph paper but rapidly that became inappropriate because of the volume of data. We recruited some staff to put data into the regional hospital mainframe and do the transformations and our graphics for us. All this trended out quite nicely, well, as a print out – in retrospect rather a crude print out – but to us it was quite exciting. We put it on the table, and we realised that the straight lines of improvement and deterioration [in graft function] crossed after transplantation. We were very keen to find out exactly when that happened because I had a theory that rejection onset might be in the middle of the night and we might be giving them treatment at the wrong time.[14]

Will: This is steroid treatment at the time? This is pre-cyclosporine?

Knapp: Pre-cyclosporine, yes. Azathioprine and prednisolone, which many people were giving in varying doses at various times, except for Mollie McGeown

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[13] Mitch, Walser, Buffington and Lemann (1976).

[14] Knapp, Byrom, Pownall and Mayor (1980).

in Belfast who gave medication once a day in the morning, with which she obtained some of the best results. We drew the two lines, or the computer did, and the lad who was doing it said: 'Is this next point on the line going down or on the line going up?' And I said: 'Well, you have to use a bit of common sense.' At that time I met somebody over dinner somewhere in Nottingham and we got chatting about this and he said: 'You want to talk to a man called Adrian Smith, who has just been appointed a professor here,' at 29, I think. He had just come up from London. I fixed an early appointment and he said: 'Oh, this is a time series. We have been handling these all the time, and we examine the trends, apply a bit of Bayesian statistics and maybe a Kalman filter, which we have been using for industrial quality control on conveyor belt performance, and any change-point will become apparent.' Michael West, who is now professor of statistics at Duke, was then a PhD student in Nottingham. He worked on our project in his spare time, and made some progress, then Adrian Smith and I obtained a grant to appoint a PhD student, Kerry Gordon, and we got to a point where we were calculating the probability of a change-point being an improving trend becoming a rejection event. I perceived this analysis for change-points as a method to transfer into the flow of all renal data, which was overwhelming us, with more patients than we could handle. We would then have an event identification process for the bone results, the haemoglobin and all the other things. I got quite excited by it, as you may know. We started to try to cultivate interest, to collect the data together, publish it and obtain more funding to further develop this approach to analysis of incoming data.[15]

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[15] Dr Martin Knapp added: 'In Nottingham we became aware of the computing development at Charing Cross when I attended a meeting in 1978 of about ten individuals known to have an interest in renal computing, held at the King's Fund building in London. The Charing Cross representative had examples of the print-outs from the prototype system in use and being developed by Professor de Wardener with Michael Gordon. I was very impressed and identified their system as a solution to organising our renal data in the Nottingham Unit before grafting on the statistical algorithms being developed with Adrian Smith for monitoring renal function and other variables. After a visit to Charing Cross, I returned to Nottingham and persuaded the local charity that was raising funds for the Unit (The Nottingham and Nottinghamshire Kidney Fund) to allocate immediate funds, which enabled us to purchase the computer hardware together with the programs from CCL. In subsequent years we had many visitors to the Nottingham Unit to demonstrate its merits and I visited many units in several countries to support demonstrations by CCL with lectures and seminars on renal computing and I also wrote articles on the topic.' Note on draft transcript, 5 October 2017.

Will: I'd like to come back to the issue of publication later.[16] The point is, this was quite sophisticated mathematics that needed computation and was one of the things that drew people into looking at the applications. Of course, nephrology is rich in a need for trend analysis of all kinds and that's another come-on; not just the amount of data but the fact that it only makes sense if it's seen as part of what went before and where it might be going. Francis, you also put the computers to particular computational uses, didn't you?

Professor Francis Dumler: This effort was started in a very unorthodox pathway. The Nephrology Department at Henry Ford Hospital had four areas. We had clinical nephrology and hypertension, we had the dialysis services, we had transplant services, and we had a basic research lab. And I actually worked on the four of them. In the research lab, we were working on biochemistry of renal hypertrophy in diabetic kidney disease, and it was a good effort. We had a grant from the Ford Foundation.

Will: You were in Detroit.

Dumler: But we had some NIH grants. In order to get NIH grants you had to re-apply practically every other year. To do them was very difficult because you could only edit one or two lines and so we spent endless hours retyping sheets. Around that time, I had the opportunity to see a demonstration of an IBM system called a Select Writer, which in today's language would be a word processor, for thirty thousand dollars. And I talked to Nathan Levin, my boss, and he went up the chain of command, and made a quick calculation saying: 'Look, we're spending so much overtime from two or three secretaries, the nephrologists are working Saturday and Sunday, 12 hours, writing these grants. Then we have to send them to the NIH by Federal Express (which at the time was very expensive). If we don't do it right, we don't get the money, so that's a minus X.' And they decided to buy the system to write grants. But the reason I chose that was that it had the opportunity to run under a CP/M (Control Program/Monitor), so you could use it

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[16] See pages 50–52 and 101.

as a regular computer and program it in Basic. So having that we already had a computer in-house. The young operator for that machine was myself. And around that time I had this Timex Sinclair model at home, so I wrote the programs there.

What we did was ask: ‘what do we need in the clinic?’ We were not thinking about transplantation or dialysis but in the clinic we had patients coming and we needed to do calculations. So we started with the calculation of estimated GFR from creatinine clearance. We did that with 24-hour urine measurements of creatinine and urea clearance, and estimated glomerular filtration rate as the average of both. We did urinary urea nitrogen appearance rate and, around that time, we had started to get a lot of referrals from Urology. Urologists would see a patient with calcium (kidney) stone, take it out and then they went home and nine months later they came with another stone and they again took it out. So we said: ‘Well, we can start a renal stone clinic.’ And when we did that, I used the calculations that Charles Pak in Dallas was using, so we started collecting all the 24-hour urine values, trying to calculate the supersaturation index. It wasn’t as good as what he did, but it was an approximation. So that was another calculation.

Will: So this was a risk analysis? Or it became a risk analysis?

Dumler: Yes, right. So, in other words, at the end I was a little more didactic with them: ‘How much is your calcium? How much is your uric acid?’ All the bad elements. Calcium, phosphorous…

Will: But you needed a computational background?

Dumler: Correct. So we did that and our hospital also had a very good pharmacy service but we didn’t have anyone that did pharmacokinetics, so we started writing the first order kinetic equations for tobramycin and gentamicin, primarily. So we had all these computation things.

Will: These were preoccupations of clinicians everywhere at the time, weren't they? The gentamicin dosing was difficult for a lot of people. And then you went on to another sort of statistical analysis with renal artery stenosis, is that right?

Dumler: Right. That came a little bit later because I was having a hard time putting the Bayesian model into the Basic that I was using. And my programming was not as good on that. The first two to three components of the diagnosis worked; when you were going up to eight or nine, somehow I was losing the loop. So I said: 'Okay, I'll put that on the side.' And then we started looking at reciprocal serum creatinine. I happened to hear Dr Mitch do the presentation, I think that was around 1974 and he published a few years later.[17] So we fitted those models in and that seemed to be particularly helpful. Now, as a side to that, a few years after that, because we had a very large dialysis population and we were a vertical system, I got all the pre-dialysis serum creatinines of all our patients that were on dialysis, and I had about 200 of them. So we entered them all by hand and we knew what the outcome [the time of introduction of dialysis] was, and it turned out that the reciprocal was very helpful except for one thing: about a third of patients fell off a cliff about three months from the actual time that dialysis had had to be done. So it was a very good estimate but you had to keep in mind that, as the values were getting lower and lower, there could be a risk. And in hindsight I think that may have been non-steroidals, hypertension, something else, at a level of renal function that was very low.

Will: There's a question of the renal replacement elect, isn't there? You get to a certain point of deterioration and eventually it's not going anywhere else. But that's another story. But the point here was that you were programming. I mean, most of the clinicians, the vast majority, weren't programming; they were using other expertise locally to collaborate in various investigatory and management issues. I was interested in how far computation was the draw towards the computing at that stage.

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[17] Mitch, Walser, Buffington and Lemann (1976).

I think we should move on to have some description of just what that hardware and software represented in our context. Microcomputing didn't really feature very much, although one of the very earliest applications was in Hull, where Malcolm Farr and Malcolm Kilvington actually set up a limited, but nevertheless working, clinical summary system on an Apple computer. This was reported in 1979 quite extensively in one of the conference proceedings.[18] Most of everything else that we've talked about turned out to be, at that stage anyway, focussed around minicomputing. And Conrad, you could give us some insight as to what was available sequentially in that area?

Mr Conrad Venn: I joined up with Mike Gordon in late 1977. I was halfway through a BSc course at Imperial College and I was approached by the assistant director of my department who asked if I'd be interested in doing a bit of moonlighting. So I met Mike and we had a chat about the project that he was working on. I don't know whether you want Mike to talk about the research project to some degree first?

Mr Mike Gordon: I'd be happy to say something.

Venn: I think the context is really useful. I can't speak of your experience before I joined the team. I can continue from that point.

Gordon: Well, there were about three or four steps that led to it really. At university, in 1958, one of the people doing a maths degree was looking at the design of logic circuits, you know, which were what computers run on. And I thought this looked very tedious, and that was the impression I had of anything to do with computers, but then in 1965 I got a job in the Electronics Department at St Thomas' Hospital, which was a pretty bright place actually. And the bloke that was running it, but about to retire, was a man called Peter Styles, who was extremely forward looking. One of these people with no formal training but an absolute instinct for things like circuit design and he was also interested in

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[18] Kilvington and Farr (1983).

computers. So I got involved in a survey of how a mainframe might be used in a hospital in the various departments. It was a mainframe because there wasn't much else. I got really rather interested in this, did a complete design for what people would look at in different departments and how it would work. It was all on paper of course because I'd only read about online-computers with multiple screens.

Then at some point along the way we had a visit to the MRC, a sort of general 'find out what they're doing' visit. And they had, I think it probably was a minicomputer, but all the output was on a teletype, as things very often were. You typed and told it what to do. And they ran a program where somebody typed something, probably a question, I don't know, into the computer, and the thing answered on the spot. I thought: 'Well, this is a different dimension. This is an entirely different thing. Here's a machine speaking to the person who used it'; so I thought: 'Okay, well probably they're not boring actually.' And in 1972 it led to my being offered a job at Charing Cross Hospital, where there was a project to put in one of the first Patient Administration Systems (PAS), which the Department of Health had become keen on. I think about 5 out of the 13 they had, or something of that order, probably more 7 out of 13 failed, which put the Department of Health off the idea for a long time afterwards.

I got involved in that and it proved to me that computers actually are boring; so I was right the first time. Well, this was the age of the mainframe, in an air conditioned, glass-walled room tended to by high priests and no one else was allowed in there and so on. I had to go and interview a number of clinicians as to what they wanted from computers and more to the point, what their departments did. One in particular refused to tell me anything – I don't know what his reasons were. Then I got to interview Professor Hugh de Wardener and this seemed to be somehow at a different level. So much so that I think it was probably the second time I interviewed him, I told him I was supposed to be doing either an MSc or a PhD, which wasn't really going very far, that was on computing in medicine. And I said: 'How would you feel if I did my PhD around your department?' He thought for about 30 seconds, and said: 'I can't imagine why I wouldn't be delighted.'

And so I jumped ship. Frankly I really didn't know what exactly I wanted to do. I had some idea that the exciting bit of computing was to do with computer graphics, this was when objects were being mathematically modelled and simple animated films were first being produced.

Will: Can I interrupt and ask you about the graphics because that really is a core issue, or became something of a core issue, because most of the people round the table have an instinct for the clarity and usefulness of graphics, which we found many colleagues never develop. But I think Hugh himself found them particularly interesting and I remember you mentioning that he saw every haemodialysis as an experiment of salt and water physiology and wanted to see it described as an entity, a graphical entity.

Gordon: Well, what he understood when I said computer graphics was something utterly different from what I had in mind. I had no idea how they could be used, but it was one of the few things I knew was going somewhere. However, he rapidly explained to me that he wanted graphs of physiological variables over time. I had a good friend at Imperial College who arranged that I could do some experimental work with the set up they had, which was indeed a mainframe linked to the big university mainframe, but also to a subsidiary mini-computer, which was quite powerful. It had an enormous graphics screen, about this much across [stretches arms out to gesture]. They got it from the Cossor company who I think really made them for air traffic control. And it was all very high tech and quite exciting.

Will: So your hands then just actually outlined a 24-inch television screen or something like that.

Gordon: Yes, something like that, and this era was such that I was terribly impressed, because I had worked in a place in fact where there were no digital devices; they didn't exist. There were no digital voltmeters and no digital anything. And this screen had at the bottom a rolling digital display of date and time. Every so often the whole complex would crash, and it had to be rebooted. Then you had to speak on the intercom to an operator in Guildford Street at the University Mainframe Centre, and he would restart everything and presumably so would the operators at Imperial.

Will: So the computers were a cottage industry as well? [Laughter]

Gordon: Well, this was what is interesting, at one point I asked the operator how they set the time. I thought: 'This is at least linked to Greenwich' or if they had atomic clocks, or whatever, and he said: 'I set it by my wrist-watch,' which of course was a wind-up wrist-watch since there were no digital wrist-watches. So this entire several million pounds worth of equipment at each end was set by this bloke's wind up wrist-watch. Indeed, the programmer who was in charge of the Charing Cross mainframe project had a wrist-watch that was always at least 20 minutes wrong. He had to make a mental correction in order to arrive in time for meetings. This was when I began to understand that, you know, technology is out there, and the world is really here at the moment.

Will: I shall interject then a little bit more about the graphics. Brian Junor should have been here but unfortunately couldn't make it, but he remembers going to a demonstration of your system in 1979 at the European Dialysis and Transplant Association (EDTA) annual meeting. He'd just finished a thesis on the use of Vitamin D in renal patients and he'd had to draw a very large number of graphs of sequential data. He was bowled over by the fact that this could be done electronically because he'd just spent an enormous amount of time, rather as Francis was describing about the grant applications, doing it by hand. It was the display that absolutely sold it to him.

Gordon: This does lead on now immediately to graphics because some of the experiments I did with this kit, with the help of the Imperial College computer department, took some of the dialysis results and then started looking at them in different ways. These were mostly variables like blood pressure and some dialysis data, flow rates etc. I had the display split in two so you could see one set of information against another set, and I think we had one display with four sets. One of the most interesting things was that when I displayed only the increments, as straight lines, that occurred during dialysis – I'll have to leave aside the exact details because I can't remember after so long – it showed that where blood pressure had gone very high, and so a lot of water – I hope I'm saying this right – a lot of fluid was removed to correct it, then the next time the blood pressure went even higher. And this, it seems, was because there was a delayed effect from the fluid removal. Unfortunately, I no longer have the photos that we took. But the long and short of it was there was an unknown time lag which was occurring.

Will: Which was revealed by the plotting?

Gordon: It was revealed when you looked at these lines, which were just the increments or decrements in the blood pressure.

Will: I hope a clinical comment from the technical side doesn't open the floodgates. [Laughter]

Gordon: Nothing I've said changes the …

Will: I appreciate your modesty, but we've got you, as it were, into Charing Cross working with the clinical material.

Gordon: Yes, and then, as I recall, we acquired a minicomputer. For a time they let me work on the minicomputers at Imperial, which were the hot new thing. And then the Professor got one and then I discovered that programming is not for everyone [laughter], and I discovered this in various, sometimes embarrassing, ways. But the Professor was not a man to be deterred. Then my good friend who introduced me to the Imperial College set up I'd worked on, said: 'Ah, you might be interested in this chap. He's a student who they're saying is about the brightest thing they've seen for the last five years. It's a bit difficult to actually get him to do too much coursework [laughter] but would you like to talk to him?' I said: 'Yes, I would like to talk to him.' So at the end of 1977, Mr Venn arrived and he said he was very keen to see what I was doing, and here I have to speak the truth, Conrad. So I showed him the minicomputer. I think it was one they had at that point in the medical school.

Venn: It was a PDP1140 in 5 East 11.

Gordon: Yes, it wasn't ours I think.

Will: Shall we move on to some sort of description of that?

Gordon: As it happened Conrad arrived with a collection of paper tapes in a large suitcase saying: 'Well, I really always print the department's line printer calendars.' You know, he could do line printer art. And I didn't want to push him, so I had to wait while he printed them. [Laughter] We didn't get to discuss what I had planned. But subsequently, with Conrad working part-time while he finished his degree, everything went wonderfully. The only other thing I will say is what I discovered while working on the mainframe – as I said it was the era of the glassed-in mainframe. I also like to call it the 'era of butterflies and mainframes', because I had occasion to meet with, I think he was a systems analyst come salesman from ICL (International Computers Limited), which was then *the* British computer company. It had largely absorbed the others. And when he was explaining to me what their machines would do, I asked: 'How did you get into computing?' He said: 'Oh, I was working in the butterfly section of the Natural History Museum and I saw this advert in the paper, which was rather well paid, for people to teach programming. So I got the job and I taught programming. Each evening I read the manual which explained how to do programming. Then the next day I explained it to the students.' [Laughter] And that was about the height of expertise in computers, but fortunately we had got ourselves an expert. Interestingly, as the Professor was keen on graphics, he quoted me one of the great clinicians of the past, I forget the name, who had said: 'When in difficulty, draw a graph.' He tried to find the reference but he couldn't.

Will: There was a strong tradition in other countries of graphical presentation, in particular I think in the Netherlands there were protagonists, but I think it was relatively underdeveloped in UK journals. Conrad, can you tell us something about hardware and software.

Venn: Sure. Well I came in on this research project, as I said, in late 1977. I saw this minicomputer. Up until that point I was not really interested in the job because I wasn't a great fan of working in hospitals, so the fact that it was a PDP11 was a great attraction to me because that was the up-and-coming machine of the day. We were taught PDP11 Assembler at university but we didn't actually have a PDP11 at the college. One of the PhD students had written an emulator on the IBM mainframe and we had to submit our macro assembler coursework on punched cards and we got the output the next day, which was a bit bizarre. I wasn't very happy with this situation, so a couple of chums and I had a bit of a poke around and we found another department associated with the computing department, who actually had a PDP11 but it was hidden away inside another machine pretending to be a disk controller. But we found that we could get access to it and we then proceeded to use that to do our coursework.

Anyway, I arrived at the hospital and spoke to Mike – it sounded like an interesting job. I saw this PDP11, which was in a big 6ft rack cabinet, had huge disk drives – these disk cartridges which stored about 2.5 MB each. So it had a total of 5MB. The memory size on that computer at the time was, I think 32KB of Random Access Memory (RAM), which got extended to the maximum it could support at the time, eventually to 56KB. I was employed to do some work to support the work which had already started. Mike was playing down his abilities as a software person but he had developed quite a comprehensive design and part of an implementation which actually saw us many years through in terms of extending the subsequent product in time in its flexibility components.

Gordon: Those disk drives were thousands of pounds each, of the order of £3,500 in the 1970s.

Will: These were the flying saucers, were they?

Gordon: Yes.

Will: Something like 2ft across?

Venn: They were 15 inches by about 1.5 inches deep, and exchangeable.

Gordon: I was going to bring one, but we decided not.

Figure 4. Removable Disc Cartridge of 2.5MB

Will: And some of them were fixed and then latterly one of any given set might be removed?

Venn: Well, some of the ones we later used had a number of fixed platters and one removable, but these were just two removable platters in separate drives.

Will: Yes, so how far was that technology taken? You didn't have more than about five of those?

Venn: No, only two. All the development work was done with 5MB total and 56KB of memory, and in that we had to fit the operating system and the application, including multiple users. I think at Charing Cross, the project was to computerise the Renal Unit and when I arrived the main aim seemed to be to solve the problem of the size of the files, the records that were growing, and to get all that data available on the computer and to present it to the clinicians in a way that would make sense to them, to highlight key points.

Will: How far do you think the constraint on size of memory influenced the programming, in the sense that there must have been a tremendous pressure to condense and rationalise the software, in the way that austerity has its effect on clinical process.

Venn: Absolutely, yes, putting all that into 56KB of RAM (Random Access Memory) at run time.

Will: So there was a discipline imposed by the sheer absence of space?

Venn: Oh, absolutely. We had to use specific techniques in order to maximise the usage of memory and also disk storage.

Will: Did that, to an extent, characterise the ultimate software product, do you think?

Venn: Yes, it did, yes it did definitely. And even now systems that derived from that, the database sizes are tiny compared to modern day equivalents.

Gordon: Remember the compressed date format?

Venn: Oh yes, we stored everything in binary format and we didn't waste any bytes at all. Everything was compressed and there was no wasted space there at all.

Gordon: It didn't work past about 1980, did it?

Venn: Well, we ran up against a number of limits in the hardware and/or the way that we designed the software so we had to re-engineer at various points. We used a single 16-bit integer as a record number in the database and so when we got to 64,000, 65535 records, then we hit a roadblock.

Will: So what were the technical developments that you took advantage of after that?

Venn: Well in that case we just re-engineered it to use 32-bit integers instead of 16, and we've gone beyond that again. So there were a series of evolutionary steps. But one of the biggest challenges at the time was just the limit of the amount of Random Access Memory to fit an operating system and the application, and multi-user at that, and we had to use techniques such as shared libraries of code. So most of the code was actually shared between multiple users. You didn't have a separate program running for every user; you had a tiny little stub of a program which then called into a central re-entrant library, which was shared between everybody.

Will: Is this dignified by a jargon word like 'lean' or something like that? Because that's what it brings to mind, doesn't it? Lean this and that.

Venn: Well, lean is a good word for it.

Will: Was it current? I mean were people conscious of it?

Venn: I don't think so. I mean a lot of people on mainframes wouldn't have had these same constraints, I don't think, because the limits weren't nearly so severe as these first number of minicomputers. The first minicomputers were fairly limited in their storage capacities.

Will: So this was a virtue of limitation?

Venn: Oh, yes, yes, absolutely. Well, it's a necessity. No other way to do it.

Will: And then subsequently I seem to recall changing machines and operating systems and (programming) language even.

Venn: Yes, yes, that's right. Well, to start with the only way we could fit everything in was to basically write our own operating system, and Mike had a contact, a chap who did some work for us.

Gordon: Chris Good, who was one of the support people from Digital Equipment, who made the minicomputer. He was a very entrepreneurial character and he offered to help. I think we did pay him something, it wasn't very much. I should say all this stuff came out of the Professor's own funds within the medical school.

Will: When we were all very busy clinically we didn't have time for publication or applying for prizes but was this condensed, as it were, software ever offered for approval to other people?

Venn: We did demonstrate it to the British Computer Society, didn't we?

Gordon: Yes, we did.

Venn: And we got an award for it.[19]

Gordon: Oh yes, we did, that's quite right. The thing is, Chris Good offered to help with the project but what he really wanted to do was to write his own operating system because these things are, you know, the technical heart. They are for the programming high priest characters although even then not many of them are at that level, and he was a hot shot. But that's what he wanted to do. I couldn't get him to pay any attention really to the project as a whole.

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[19] Mr Mike Gordon added that this was a national award for software design. Note on draft transcript, 18 September 2017.

Will: The physical consequences of the available hardware actually came then to users because we couldn't use the later systems in rooms that faced south without blinds; they generated heat and that had to be taken into account. There was a certain amount of sound; there was always a good deal of housekeeping involved in the hardware maintenance. Is that fair? It probably became simpler but we never really got entirely away from the notion of hardware in separate spaces with air conditioning. There was an argument I remember about whether we needed air conditioning in one of the particular rooms.

Venn: Well, the minicomputer that I used first at Charing Cross had some air conditioning in the room to keep it cool.

Gordon: It wasn't in a glass box, though.

Venn: Well, no, but the later, slightly smaller boxes, didn't need air conditioning but would get hot if they were in a…

Will: Did other clinicians have the heat nuisance problem? Because it was, in the end a revenue item or a capital item, wasn't it? Did you have air conditioning with your room?

Sells: Yes.

Will: So that was one of the knock-on consequences of the hardware installation.

Venn: But when I joined, as I said, the focus was on getting the data stored and that was the first thing, and then getting it easily accessible to the clinicians. The first application when I arrived had a conventional menu system, which was difficult to use, so we had to work on ergonomics, and that's when we designed the 3x3 menu navigation with the key pad.

Will: Which was highly successful.

Venn: It was, I suppose, a lucky accident in a way but it was based on some work that Mike had started, again he had some ideas which he described to me and from that I was able to come up with the 3x3.

The graphics. To start with it's the data story but along with that was the graphical display and to start with we were just drawing time series graphs of urea, creatinine and calcium, phosphorous, but it was a bit later on, with feedback from initial customers, they said: 'Well, what about doing reciprocal creatinine?' So, with the data there, we were fairly easily able to add a function to allow reciprocal of any variable, or products of variables. But anyway, as it happens, it coincided with my graduation and happily I was able to use the project as my thesis, so I didn't fail my course completely. In fact, I came out with a 2:2, which I was very happy with. For me it was the wrong course. I was in the right place at the right time to meet Mike and to form the beginning of a successful, I think, career, and we demonstrated the project as it was at EDTA in Amsterdam in 1979.

Will: I was interested to hear how EDTA happened. I mentioned already that Brian Junor, among others, was there and that was one of the main early clinical exposure points of the system.[20] I gather that when you got there, things weren't quite as they should be? Just tell us how that came out.

Venn: No. We'd shipped over a significant amount of kit with us, including a prototype graphics box, which was a big rack-mounted cabinet about 20 inches cubed, which by some means had been dropped from the aircraft on unloading and seemed to be quite badly damaged. But, having removed all the prototype boards and straightened them and put them back in again, miraculously it worked. We got to the conference centre and we were expecting to have a stand in the commercial exhibits area, but they knew nothing about it; they knew nothing about us. And in the end, after much negotiation, they said: 'Well, okay, there's a bit of an area here at the top of the stairs where the delegates will come up the stairs from the conference sessions .' So we were the thing people saw as they first

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[20] See page 25.

came up the stairs, which I think was a very happy accident. We set up the computer and a terminal and the big graphics screen and we just implemented a feature to show some fairly crude images of the idea of patients' photographs as one possibility, and we had a rather attractive young lady who obviously, I am told, was not a dialysis patient. But we weren't showing any personal data.

Will: So you were short of second hand car salesman flags, but you were in a very good place. So it was partly the product and partly the incidentals of advertising that kick-started CCL!

I want to next discuss the start of the British Renal Computing Group, how that really occurred and to some extent why, and I've asked Robert to make some preliminary remarks while we move around that topic. Thank you, Robert.

Sells: Someone asked for a 'Bon Mot' to summarise our history so I spent some time last night thinking and came up with 'The age of Clinical Onlinement'.

From 1971 to 1980, I spent a lot of time getting very angry about data. The reason was because in transplant surgery data was coming at me from all angles. I was not like you physicians, calibrated to receive and interpret data. For you Physicians your data was actually the stuff that helped you to make a diagnosis and to decide your treatment. In general surgery of course regular, huge, data dumps were not necessary. You will all remember the one-metre-long charts on which we recorded the 90 or so parameters that we measured daily on our patients. The immunosuppressants were blunt-edged, bone marrow toxic and idiopathically dangerous, so rapid changes in treatment were often required. Until we got some sort of automatic data transfer from the labs, we wasted between 20 to 30 nursing hours per week and 5 to10 doctor hours per week actually transcribing lab results on the telephone. Imagine Saturday morning, me on the phone: 'Mrs Bloggs, sodium 137, thank you, creatinine 280, thank you, urea 19, yes …' The system didn't really work at all well. So therefore everything turned into a dream of comparative ecstasy because of CCL. And I can remember so vividly the way in which it happened.

Stella was a dialysis patient in the Isle of Man, who wasn't on the Liverpool list, but she wanted a transplant desperately. She was diabetic, she had a malignant microangiopathy, being young and non-compliant, and she was a teacher. Cyclosporine was being used but only as part of the European multi-centre trial protocol but Mike Bone and I had set our faces against transplants in diabetics because of the disastrous results revealed in a recent audit of 25 patients given Imuran and steroids, all of whom had died after transplant. I told her that her life would be better, would be longer, if she stayed on dialysis; that turned out to be true but sadly she did die in 1980. After a bit, her solicitor called and, to cut a long story short, the Unit inherited about £110,000 from Stella's estate, which triggered an emergency meeting between me, Mike Bone and Geoff Taylor (then a nephrology registrar).[21] We decided to go down and see the Charing Cross system, which two of us did. Barbara Temple was appointed that year (1981), we bought the system, and life changed very much for the better.

It changed not just simply because a surgeon suddenly became numerate, which I certainly did. It was also the fulfilment of a long-held dream: In 1967 I had approached my brother-in-law, Andrew, a very talented engineer/computer designer. I said: 'What I want from you is a series of plots on a computer, which are drawn up as a curve which shows us what the serum creatinine has been of these patients since the time of the transplant.' He didn't understand really what I meant until I told him several years later that if he had thought of an answer, there was no need, because Mike Gordon and Conrad Venn had done so.

Looking back, the appetite for this sort of technology was enormously important but without the prepared mind you may miss something which would have turned, if noticed and exploited, into something miraculous and life-changing. We were actually hungering for rationalisation of numeric data storage and retrieval, though the transplant community in general may not have understood that need. You physicians, on the other hand, have always been required to act quickly for

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[21] Professor Mike Bone added: 'He was very, very bright, and left in 1981–82 so as to specialise in Intensive Care.' Note on draft transcript, 12 October 2017.

the prevention of pathological renal injury or recurring disease or maybe saving a life, and an essential part of your rapid response kit is the prompt return of results of blood tests. Kidney transplantation required that every member of the team should develop the same rapid footwork. Until we had CCL, effective clinical decision-making was obviously impeded by poor communications with the lab.

In the 1970s transplant surgery, before cyclosporine, the morbidity and mortality in the patients that Mike Bone and I treated, were absolutely terrifying. I can remind you of some of the figures very briefly: at the end of six months, 50 percent of the patients had lost their grafts; at the end of a year, one quarter of the remaining patients were dead, mainly due to sepsis and coronary thrombosis because of overdose from steroids and Imuran. About 5 percent of those cases died of inoperable haematemesis: we frequently found that sewing divided gut tissue was rather like suturing watermelon, the tissue being profoundly depleted of collagen by high-dose prednisolone therapy. In some cases, there appeared to be no fibrous tissue left at all. Surgery did not delay death and sometimes brought it forward.[22]

During 1978–1982, the Liverpool Unit was deeply involved in the Sandoz European multi-centre study of Cyclosporine A.[23] Access to CCL helped us to store and present relevant data in this prospective randomised study, first of all, and then the routine application of cyclosporine (Neoral) as prophylaxis. This would have been difficult without CCL. We had immediate access, not just to standard physiological parameters, but new variables such as trough and peak cyclosporine blood levels, area under the curve, and reciprocal semi-logarithmic creatinine plots had all become crucially important.

Will: Robert, could I put a pointed question to you about how the immediate post-transplant ward felt before and after cyclosporine? The relevance of this will become apparent later. CCL was critical, the data-handling was critical. Was there

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[22] Professor Mike Bone added: 'It was certainly bad before I came in 1975, but I believe it had improved before the Pancreas programme started.' Note on draft transcript 12 October 2017.
[23] Calne and Wood (1985); Beveridge and Calne (1995).

a change in atmosphere when things like the untreatable haematemeses seemed rather less likely?

Sells: Yes, life got so much easier. Several things happened all at once. Though CCL was one important factor in a time of change, cyclosporine brought a new safety because acute rejection was less frequent and less severe resulting in a substantial reduction in steroid dosage. You asked me this pointed question recently, about the cultural changes which occurred, and I didn't really know what you meant. And then I sat back and thought and yes, we had become a much more popular speciality for surgical and medical trainees. Medical SHOs loved to rotate through the transplant unit, not because of the beauty of working with Mike Bone but also because they learnt how to treat immuno-deficient patients. And surgical registrars learnt the hazards of co-morbidity. Also, we had these outreach clinics and more and more patients were referred and we started the pancreatico-renal transplant programme for a group of dialysis patients who suffered malignant diabetes, mostly young women, partially blind, with severe microangiopathy, some without fingers, all without a sex life, and all of course without renal function.[24]

Will: So these were all knock on effects of slowing down and making more controllable the post-transplant course, as it were, among other cultural developments.

Sells: Yes, let's not forget this. I can attribute a lot of success to CCL but no therapeutic benefit improved as a direct result of your work except that we found life so much easier to work with our patients, and that did produce a cultural change.

The third primary benefit was entirely in our housekeeping. For the first time it became possible actually to transfer data from the referring centre like the Isle of

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[24] Professor Robert Sells added: 'Discharging successful recipients ten days after surgery, off insulin, off dialysis, on a full diet and a restored, active social life did a lot to raise the morale of the entire staff.' Note on draft transcript, 28 September 2017.

Man or Whiston Hospital or Mike's dialysis service, or the Dialysis Unit upstairs in the Royal Liverpool University Hospital, to us, and they could send stuff back at the flick of a switch. And that was tremendously important. Also, audit became much easier with CCL. Audit actually is only useful if you put the equipment that you use, and the data which it generates, to a really good use. And the best possible use, in my view, of our audit data was to compare our results with those from other units and national data. In 1973 (pre Mike Bone), transplanters were whistling in the dark and I had paired up with Bob Johnson and Netar Mallick at the Manchester Unit. Meetings were held every six months – we were that insecure! – and somebody usually presented research in progress from both units and worldwide. CCL greatly facilitated these meetings where trend analyses as well as Mortality and Morbidity (M&M) were presented. And I have no doubt that competition between each unit improved our results.

Will: That would have been called collaborative audit later. I mean, it was on a modest scale but it was one of the –

Sells: It wouldn't have happened without CCL, I'm quite certain of that.[25] Also we were a participant unit in that interesting European Multi Centre Study, a prospective, randomised trial of cyclosporine monotherapy versus Imuran and Prednisone.[26] At the same time the Canadians did a trial which, as you will remember, compared cyclosporine plus 25mg of steroid with Imuran and Prednisone.[27] The European one was a superbly controlled trial, again numeracy and orderliness of storage of data was absolutely crucial. And when it became clear, do you remember the two curves? [gestures] The experimental group is the upper line and the control group was the bottom line. At four years it was a 25 percent difference in graphs; at six years it was about 15 percent; at ten years they were identical. Cyclosporine toxicity. And up here we developed the blood levels.[28]

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[25] Professor Robert Sells added: 'And after CCL had virtually taken over the world of sequential renal data, other units from Leeds, Newcastle and eventually Glasgow came to these meetings.' Note on draft transcript, 28 September 2017.

[26] See page 37 and note 23.

[27] Canadian Multicentre Transplant Study Group (1983).

[28] Professor Robert Sells continued: 'As we now know, the early benefits of cyclosporin changed organ transplantation permanently despite the awkward finding, six years into the trial, of

Will: I should say, for the transcript that you see the whole thing diagrammatically, and you're actually, hands in the air, describing these curves, that move.

Sells: But did you understand what I said? [Yes] Ah, wow.

Will: But that's precisely what the display of data did on a routine basis and that's exactly right. I really want to get back to the narrative of the BRCG. So there was a kind of ferment in the early 1980s arising out of people using systems of different kinds for different reasons, along the lines that you mentioned and others (even the Government was involved with their public initiative, The Information Technology Year IT82). I believe that Martin and others were agitating, if you like, to try to pull this experience together. I mentioned an editorial in the *BMJ* in 1980[29] and there were other little bits and pieces going on. There was a meeting at Tavistock House in early 1982, after a Renal Association (RA) meeting, about setting up some sort of UK computing group. It wasn't fully enabled at that point and historically, I think, you, Robert, were the Chair of a meeting at UK Transplant Service (UKTS) at the end of 1982, where this crystallised in some format, with I think Neville Selwood and Mollie McGeown, is that correct?

Sells: Yes. After Mollie succeeded Tony Barnes in the UKTS Chair. I don't remember very much about the detail but in the UKTS Management Committee we discussed CCL, its nationwide deployment and its possible networking role, with the EDTA registry.[30] Neville's position was awkward because of a possible conflict of interest. I think Martin Knapp may know more….

Will: Well, Martin wasn't there. It's one of the interesting points, because he wasn't there and wasn't part of that crystallisation. It's my understanding that at

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cyclosporin nephrotoxicity. And this spawned the new industry of drug level monitoring which generated yet more numbers on each recipient. So CCL scored again.' Note on draft transcript, 28 September 2017.

[29] Anon. (1980).

[30] Although the EDTA extended its title in 1982 to EDTA-ERA we shall refer to the Registry and data returns as simply EDTA related throughout the transcript.

the time, he felt that there should be some sort of renal IT group but that it shouldn't be affiliated to an establishment, mentioning UKTS and EDTA, and what the UKTS initiative did, because it came out of a meeting held at Bristol, it hinted at some kind of affiliation and there was correspondence about that at the time. It wasn't right or wrong, it was an issue of preferences and interests, I think. Martin.

Knapp: Well, my memory of that time is patchy, partly perhaps because of my pre-occupation with some personal pressures and a move from my NHS position. Earlier in 1982, I had been keen to get a picture of the IT in all the renal units, having sensed the potential from the US and my exposure to CCL in the UK as the first user of the commercial CCL system. I had sent out a national round robin enquiry and used the October 1982 RA meeting in London as a convenient meeting place to talk about it. I wrote up minutes and we planned another informal meeting at the UKTS at the end of the year, so that we could include all other interested parties. It had become obvious from my survey that several London and other centres were taking local IT initiatives other than CCL and no renal surgeons had been at the RA meeting. A national demonstration meeting was planned for Leeds in early 1983, as well as one in Nottingham in September. As I was in the process of leaving the NHS across this period of time, I was able to spend more time on exploring clinical IT and my other interests like Chronobiology. I had not had enough space in my busy NHS consultant post to develop my intense interest in these topics. I had already set up a small academic unit at the Nottingham City Hospital linked to the Renal Unit to study biological rhythms, especially in relation to immunology and transplantation, as we discussed earlier. I was developing existing links with Nottingham University and I was able to do more IT development through a new Unit of Medical Information Technology. Looking back, I wonder if the UKTS meeting went ahead without involving me in the subsequent structure of the BRCG because I was perceived to be too involved with CCL, the commercial aspects of clinical IT.[31]

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[31] Dr Martin Knapp elaborated: 'Having looked at the letters of the time it is clear that I, among others, was known to be cautious about a new special interest IT group being linked to established bodies like UKTS, EDTA or the Department of Health (DHSS), and preferred a looser and more informal group. It seemed to me then that the NHS bodies were monopolies that should each have only a piecemeal role in a much wider Renal Computing Group. We had already found out that the DHSS would not offer any secretarial or other support to a stand-alone IT group in the near future.

Will: This speaks to the proposal that the meeting voted on, and I have the record, which was 'to support the coherent development', a phrase I think was introduced by Robert at the meeting, 'the coherent development of computing in renal and transplant units in the UK. The proposal was adopted by a show of hands'. So that was the origin of the group and, apart from freedom of membership, there was no other stricture put on it. Clearly there was a UKTS connection, where Neville Selwood talked about offering to host a secretariat and it was given out that had been credited with the approval of the UKTS management committee. Now, I think that Mollie McGeown was the medical person running the UKTS.

Sells: Yes, that's right.

Will: One of the really interesting things about this, of course, is that it presaged the arrangement that the UK Renal Registry (UKRR) used under the auspices of the Renal Association in 1995 to start up their proceedings. They did have 'secretariat and personnel' and they did take advantage of the fact that it was an established body that could receive funds etc. But the computing group never actually got to that point.

In my absence in the US, which was well known at the time, the UKTS meeting took place and the BRCG was formed by show of hands. I gather that no link to UKTS itself was discussed, although there was some hope of support from there.* It is worth mentioning that there was much more mistrust and discomfort with commercial interests in the 1980s NHS. Once outside the NHS I developed a company to raise capital and attempt to get grant funding to promote both renal IT and chronobiology research, which later failed. I did move my research group to the University Department of Obstetrics with Professor Malcolm Symonds for a time, where we focussed on the usefulness of clinical IT for managing delivery etc., as well as developing our methods for monitoring clinical progress and then promoting the algorithms and the software to implement them in several specialties. A possible suspicion of commerce is detectable in the constitution of the new BRCG, which stated that members "should be interested in or working clinically in nephrology" but membership "was not to be available to those with a contractual commercial interest". I was in the UK up to 1986 and was disappointed not to join in with the group that I had been pulling together pre-1983. My connection to CCL was never contractual but it was close and the concern in the clauses about commercial involvement seemed clear to me.' Note on draft transcript, 14 October 2017.

*Dr Es Will added: 'No support from UKTS or DHSS was ever forthcoming, after a formal approach to the former through Neville Selwood and to the latter (Dr Pincherle) by myself.' Note on edited transcript, 14 October 2017.

Feest: The Registry arrangement wasn't like that. We basically got a grant from the Government to get the Registry going and we had to find somewhere, and we had to pay our way. So we weren't in any sense an arm of UKTS.

Will: I wasn't thinking of either group being an arm.

Feest: The UKTS had never actually had a meeting and said: 'We are supporting the Renal Registry.'

Will: No, I'm not suggesting that at all. The mechanisms were different.

Feest: An arm maybe the wrong word but the mechanism was we had some money and we were seeking a home. There wasn't a discussion in UKTS to support us.

Will: No, absolutely not, nor was there ever a formal UKTS commitment to the BRCG. My point is that you need somehow to recruit establishment systems when you set up things of this kind because otherwise, and this is exactly what happened to the computing group, it never has any kind of recognition or home. So in that sense a libertarian approach, where you say, 'No, this is free-running group' won't work because you can't attribute any establishment to it. That is what was thoroughly different about the Registry, given it was a Renal Association initiative, of course, and had an establishment provenance.

Feest: Can I just come back to that. I think it's different in different circumstances. What happened in the Registry was that, because we were in the building as UKTS, they started putting all sorts of limitations on what we did, so we left. Then for a while the Renal Registry was my office in Southmead. It wasn't until we got out from the restrictions of UKTS that it really got going.

Sells: I'd like to contribute something to this, if I may. I think there was a good deal of animosity and the centre of that animosity was that there was only one person who was really professionally equipped to deal with the data at the time, and that was Neville Selwood, then employed by UKTS, or was it EDTA?

Will: It was UKTS.

Sells: OK UKTS. Well, then he had a magnetic pull towards EDTA. Then there was the BRCG, about which my memory is regrettably dim. But I do remember some pretty acrimonious discussion at UKTS about how Neville's professionalism should be used. And there were people who were actually dead against Neville being involved in anything other than UKTS. So there was a sort of annealing of boundaries, and as you were talking, some of that came back into focus. It was not at all a happy scene.

Will: One of the paradoxes is that having been started in the event at a UKTS accommodated meeting, in the end UKTS played scarcely any role in the coherent development of the BRCG.

Sells: Well, they flounced, you know.[32]

Feest: They had a wall round them. Likewise, it took us years to persuade them to actually participate in any way in the Renal Registry, or to share any data or do anything else.

Sells: You're talking about the Department of Health, you see, Terry. That was the problem.

Feest: Yes, I mean it was a difficult organisation.

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[32] Professor Robert Sells added: 'UKTS was a creature of the Civil Service and was inert, and bureaucratic. It was also insecure because the incoming flood of US data progressively weakened the importance of HLA matching, which was the "raison d'être" of UKTS. It couldn't contemplate networking under that sort of chronic stress. Too risky.' Note on draft transcript, 28 September 2017.

Will: Well, I suppose that UKTS had the means to discharge the task that they felt was their core activity, which was the moving and matching of kidneys, so they had a kind of fundamental pulse, if you like, in the information handling, which everybody else was actually developing and exploring piecemeal. So there were cultural differences in what was being attempted. It is interesting that, in the end, no advantage was taken of the group *per se*, and they didn't really subsequently feature. Given that Dr McGeown was involved too at the same time, that was surprising because she was pretty convinced about the importance of IT.

Sells: But I think this is a terribly important difference between UKTS and any other Renal Registry, any other registry which is hungry for renal data: UKTS, don't forget, was put forward on the basis that tissue matching is important. In the days of Imuran and Prednisone, and before we understood the blood transfusion effect, Mollie McGeown just transfused everybody and thereby produced a form of tolerance, I suspect. That's why her results were so damn good. But she was very, very single minded about why UKTS existed, as was Tony Barnes, and that was to get renal transplantation on its feet, and to optimise results by making sure that every kidney was as well matched as it possibly could be. That was the foundation, which was perceived as having nothing whatever to do with the storage of renal data actually.

Will: Let us come back to the issue then of who were this group supposed to relate to and how was it supposed to operate. I thought of this in terms of constituencies, because special interest groups tend to have folk with even more particular interests, as we see around the table. We earlier rehearsed the constituency of unit-based computational interest and single projects at unit level, which existed in an organisational vacuum nationally, and might have gained some real benefit from having a forum of exchange. At the same time, we were developing the clinical issues of data compilation and display through CCL, and that was another constituency. Then the third one was to some extent Francis' contribution, where he obviously found an interest and value, and so did other colleagues from overseas, who are not here, to come and see what was going on and to present their work in this situation. Mike Goggin, you felt strongly about this throughout, didn't you? I think for a lot of people it was a little difficult to know what the benefit (of the BRCG) really felt like.

Goggin: Well, I think it was very clear, it was interesting to hear the discussion that's gone on before this. It was very clear that whatever happened at the meeting in Bristol at the end of 1982, the officers were appointed. You, Es, were the Chair and Neville was the Secretary, and meetings did happen. I think there was a sort of drift into it, and the drift into it came after the meeting in Leeds in 1983, and it wasn't until 1984 that an executive committee was set up. Now, I don't know how you did it, but you probably circularised all the interested renal departments and got contributions put up for the content of these meetings. I think that probably is what happened.

Will: Well, the agendas of the meetings rather fell out, but I'll address first this business of an executive. It was openly discussed right from the beginning and there were people who didn't feel it was necessary because there had been no real testing, if you like, of interest in the whole field. Terry, I know, felt strongly there needed to be an executive committee, and that was absolutely right, but there was actually some minor resistance to that from other people. As you say, it was only after a short delay, a year or so, that a committee was put together. That was a matter of intuition and, as with the Registry subsequently, there were some area representatives and there were people coming in from their own interest point of view. At that time, I didn't see the thing in terms of a constituency issue. It just wasn't perceived in that way.

It's interesting from the meetings to see what the titles were. The Leeds meeting (1983) was entitled, 'Research and Routine'. So immediately you've got the computational/data information binary there, and the posters and the topics reflected that. In fact, the Leeds Abdominal Pain programme (Tim De Dombal) was included as well. So both the research and routine elements were prominent, right from the start.

The second meeting at St Thomas' in 1984, we called 'Systems Operation in the Renal Unit'. So that showed a kind of slide towards the clinical, if you like, being more about the clinical nitty gritty. It's interesting, of course, that there was no form of systems analysis or operational research ever done on the clinical elements, as far as I know, at unit level. Then in Exeter in 1985 the title was, 'The computer-assisted renal unit'. So the agenda seemed to be sliding towards this much more clinical than research/computational element. Certainly, the communication component, which we'll talk about in a moment, wasn't reflected within the titles. After 1985 we simply had 'national scientific meetings'. We dropped any kind of specificity about the IT substrate, what topics it was covering I think the transplant interest was pretty modest, even though it might have existed, and more strongly in some places more than others. But Robert, you were pretty active in the British Transplantation Society (BTS) at that time? But you didn't develop, if you like, a computer group in that?

Sells: No, but Barbara and I demonstrated CCL at a BTS meeting in a plenary session, and there were 'oohs and ahhs' – I remember Peter Morris and Roy Calne were each, surprisingly, impressed – and then we got back to talking about cyclosporine toxicity.

Will: The things you knew about.

Sells: I can't remember that CCL was ever mentioned again at a BTS meeting.[33] Mike, were you at that meeting? The British Transplantation Society, about 1982, 1983?

Gordon: I don't think so. It's possible that Andy Webb may have gone to it, I'm not sure.

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[33] Professor Robert Sells added: 'However the Massachusetts General Hospital were very interested in our 1982 *Lancet* paper and Paul Russell asked me and Barbara to demonstrate CCL at a clinical meeting in Boston. I think this first use of CCL in the USA was a signal new achievement by the hospital, similar to the first use of general anaesthesia 140 years previously!' Note on draft transcript, 28 September 2017.

Sells: No, I think you're right. It wasn't marginalised, it marginalised itself. We had more important things to do. When I was President of the BTS in 1984, Councils' advice was: 'Please carry on with your interesting numerical experiments.'

Will: Do you think that if cyclosporine hadn't arrived at that point, the data issue might have been more pressing for transplant units? I mean the fact is it occurred at around the same time.

Sells: Absolutely right. Cyclosporine was a revolution. In 1979 we gave our first dose of cyclosporine A and those first three patients did incredibly well, no rejection, no early complications. Then in January 1980 the multi-centre trial started and by 1982 people were actually being prescribed it. So these were hugely important, earth-shattering changes, which we addressed almost to the exclusion of other things, including the development of computing systems, which we humble surgeons left in your very capable hands.

Will: Francis, what was going on in the States at that time in terms of communication of this sort of material? What was happening? Were you able to go to other meetings of this kind and present your material and join a forum with others?

Dumler: Yes, actually, we tried to send papers to the American Society of Nephrology (ASN) meetings, but at the time the ASN meetings were driven primarily by the renal physiologists. And clinicians were second tier members. Dialysis doctors were fourth tier members and the transplantation community was primarily based with the American College of Surgeons, so there was not much venue there. But there were two societies in the States, and I can't remember the initials of it, but the Electrical Engineering Society was very, very interested in systems operations and in computers. Most of their interest in computers was in using networks and using mainframes, but some vendors at the time, primarily IBM, were starting to look at entering the healthcare industry, not at the level of financing or systems operations but as administrators understanding the flow of? work and the flow of money. There were the beginnings of artificial expert systems and Octo Barnett in the Massachusetts Institute of Technology (MIT) had set up a natural language for computers in medicine and one of the ideas was to tie it to expert assistance. The Navy was presenting many grants because of nuclear subs. The nuclear subs were one year under water, their medics were well-trained, but they couldn't put a decision on a boat for a year. So the idea of these systems that would help the medics sort things were coming in.

I presented a few papers, primarily on my two base papers on renal artery stenosis and then differential diagnosis of acute rejection versus acute tubular necrosis or acute renal failure in transplants. And there was another group that really started with the Octo Barnett group and that's SCAMC, Symposium of Computer Applications in Medical Care. And that was an open venue. They got every possible phase of computers that could be applied to medicine. There were programs for pharmacology, there were programs for assisted devices in various specialities, and that was a good venue, where I started presenting not computational work but data analysis work, which is what became the Nephrology Information System. There was a lot of interaction.

Will: But there was no similar arrangement (to BRCG) and when you saw what was going on here, that seemed to have some cachet. Something that was worth coming to?[34]

Dumler: Right. You could present these things to the electrical engineer group – people understood what you were saying. But they were thinking chips, wires, other program tools, and, as somebody mentioned before, the need for having compressed data. It was interesting that the group that did the most extensive hardware/software compression were Russians, because they only had a little computer and they had to put all this stuff in there.

Will: It rather repeats the point we made earlier about condensation being a good idea in the end.[35]

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[34] Barnett (1984).

[35] See pages 30–32.

Dumler: Right, so that was nice for me to present. And IBM was interested and wanted to know if there were other physicians who were doing this because their thought in terms of the artificial expert was that they are computer people and we have the knowledge. As soon as we give them the knowledge, they don't need us. So it was basically a lot of questions and modelling and, 'when would you do this?'.

Will: And it still goes on today. The other overseas people who came in were Norbert Gretz, who was spending time with the EDTA Registry from Germany, and he set up quite a big multi-centre study in Europe using modern IT, so that was really interesting for him. We saw a model for that kind of thing. And in the end Frank Gotch came and talked about Kt/V ((Clearance x Time)/Distribution Volume),[36] which we can come back to, but there appears to have been some draw from a critical mass element.

Dumler: Right. SCAMC is a huge meeting. It's like going to the ASN now, you know, there were 8,000 people with different interests. Now, because Octo Barnett was interested in computerised medical records there was a certain tendency to pull all of that together, but nephrology was a very small piece.

Will: Martin, you were earlier showing us the volume of *Kidney International* (*KI*) October 1983 (Appendix 2), which contained a number of articles about renal IT. I'm intrigued to know why that happened, because it seemed very early for publication of what turned out to be really rather core issues, and after that most of us had an uphill job to get anything about clinical computing into the press. The bibliography shows there were conference proceedings and snippets and bits of this and that,[37] but the journals always insisted on having results from the application of the methodology. Of course, everybody was so involved in the exploratory gestures that they didn't have time, at that stage anyway, to produce hard material evidence of benefit. But it didn't matter to the clinicians. Because

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[36] Gotch and Sargent (1985). See further discussion on page 57.

[37] See Appendix 5 for the historical bibliography.

they were experiencing that benefit, they didn't need to prove it to anybody. But how did that *KI* volume come about, Martin?

Knapp: Well, I guess, sadly in a way, it was nepotism rather than quality [laughs], that is rather than the quality of the persuader. In my third year after medical school I went to Duke as a resident (registrar) and there I met the nephrologist at that time, Roscoe Robinson, who later became the editor of *Kidney International*, and this is relevant to your question. The head of medicine was Eugene Stead, who was a very distinguished clinical physiologist and had a very high reputation as an educator in the States. William (Bill) Stead, his son, later became very involved in developing the electronic computerised medical record (EMR) at Duke. They were clearly examples of people who were making progress in the USA at the time when we felt we in the UK also had made progress. In Nottingham using the new CCL system, with Liverpool and Leeds and other people, we were active and tried to push it with demonstrations, meetings and papers. I went over to the States in 1982 and arranged to call in at Duke to see my old friends. I met Roscoe Robinson, now editor of *Kidney International*, and explained the problem that you described – of getting people to learn about the application of computing to nephrology which we all thought was important. What they were doing at Duke they thought was also important and Robinson suggested that he could allocate an issue of the journal to publish a symposium on computing in nephrology, which would not just be a supplement, in the standard way of covering a new topic, but a regular issue. I was given the brief of collecting papers from non-USA sources to present the state of the art, which we had done at a number of small meetings in the UK. I have the contents of that *Kidney International* here if people now want to see them. Hopefully they are going to be archived.[38] That's how it happened. I don't think it's simple to assess whether it had any impact in the world.

Will: Less than we might have hoped at the time. [Laughter]

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[38] For the *Kidney International* contents page, see Appendix 2.

Knapp: Most people probably left it on the shelf unless they were looking up some topic that interested them. It is a record of progress in some units. I was given the job by people who knew me and hopefully respected me, but also had their own agenda to promote their ideas and their methods. The authors I asked to contribute were chosen by me from people I had a respect for. They were only some of those who were doing useful computing in their renal units, so it wasn't in any way inclusive, and it could well be I offended some people by not asking them.

Will: Well, in the event then, the computing group ran six annual national meetings, which most people will recall vaguely, starting at Leeds, then St Thomas', Exeter, Warwick, Canterbury and Glasgow. There was a consultant seminar inserted in 1986 on clinical renal computing connected with the Leeds Renal Association meeting, so people could have taken advantage of educational and other experience that was available to them. It's difficult without going into too much detail to describe all of the sort of functions and breadth of those meetings.[39] There was additionally an issue about information exchange, which we partially mentioned, and a series of concerns about access to data, which came from the current clinical databases. To that was added computational interest in urea kinetic modelling, in risk factors, and in the trend analysis that we've rehearsed, and the introduction of the Bayes probability structures. So that was the clinical side of it.

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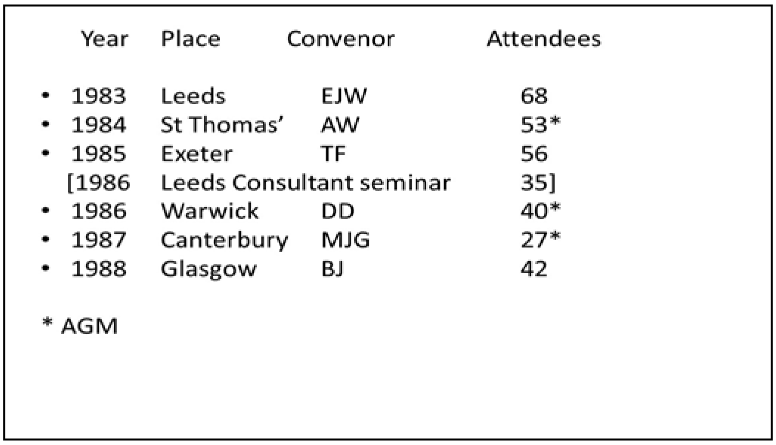
[39] See sample programmes in Appendix 3.



Year	Place	Convenor	Attendees
• 1983	Leeds	EJW	68
• 1984	St Thomas’	AW	53*
• 1985	Exeter	TF	56
[1986	Leeds Consultant seminar		35]
• 1986	Warwick	DD	40*
• 1987	Canterbury	MJG	27*
• 1988	Glasgow	BJ	42

* AGM

Figure 5. BRCG Annual Meetings

As far as the Department of Health were concerned, there was obvious interest in planning the renal (replacement) programmes, because they were faced with demand and had to allocate resources. There were one or two contributions from modelling the planned development of renal departments, but the planning models didn’t really come home until there was a substantial change in attitude in the Renal Association about getting involved in the politics of maintenance renal replacement. That change presaged surveys of renal failure, and subsequently formal epidemiological work, which led to a broader, deeper and more informed analysis. But the BRCG were not *per se* connected with those descriptions, although obviously information was available from what people had been doing from their current clinical databases.

If there was a major reflection of any coherence in renal IT development, it probably was in the EDTA Registry returns, because we were able to have joint activity on a collaborative basis with CCL and that operated in a progressive and incremental way. UKTS was not involved in that. The EDTA-ERA itself did partially reflect the computing changes in their report of 1984 and Neville Selwood was increasingly involved with them. There was a comment about computing in renal units growing throughout Europe and on average 10 percent of units reporting to the EDTA Registry had their own computer.[40] There was a figure that showed a

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[40] EDTA Proc 1984;21:68

preponderance of such systems in the UK, which was clearly the spread of the CCL system.

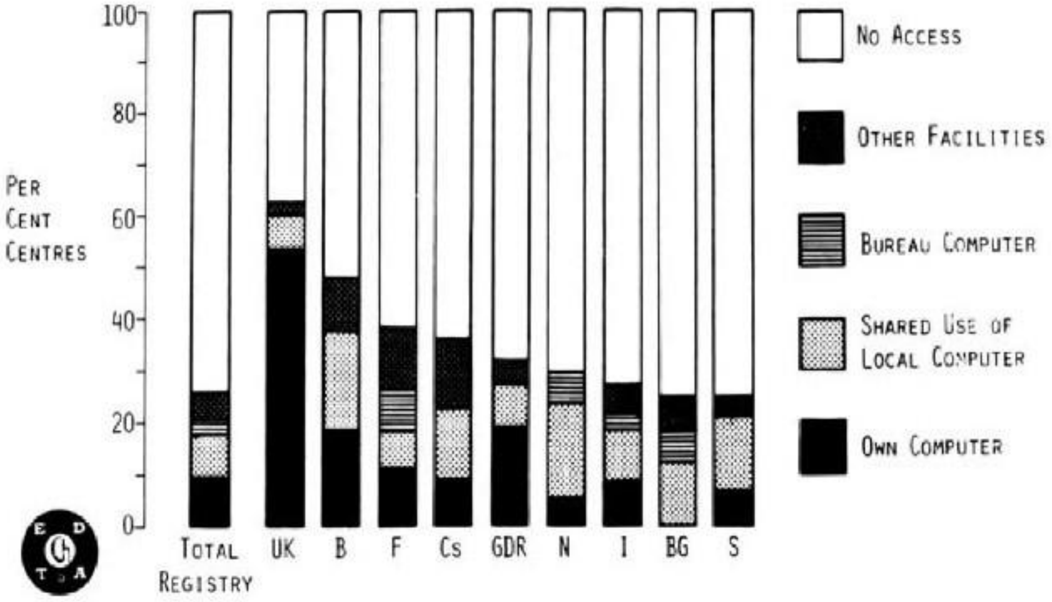

Figure 6: Type of computing facilities available to renal units in selected countries. Those shown returned more than 15 replies, and contained at least 25 per cent of centres with facilities. Total Registry, UK = United Kingdom; B = Belgium; F = France; Cs = Czechoslovakia; GDR = German Democratic Republic; N = Norway; I = Italy; BG = Bulgaria; S = Sweden. Reproduced from EDTA Proc 1984;21:68, Figure 43.

And never mind 10 percent, it was over 50 percent of UK units that already in the mid-1980s had access to systems, which were developed enough to be able to return data electronically to the registry. This was quite different from Europe. Presumably part of it was the size of the country, part of it was the NHS itself, and the integration element. But it was also partly a reflection, if you like, of coherent development. How much it had to do with the computing group remains to be seen.

So, moving on slightly in terms of topic, the annual EDTA Registry returns had been going for two decades essentially, but they became increasingly difficult for the UK units to manage, partly through a growth of numbers, which was 6–8 percent per annum in West and North Yorkshire, for example. There was a very poor return in the early 1980s from the UK. It was all done on paper and the items were very heterogenous, for example 'yes' or 'no' could be conveyed in different ways, and so it was really quite a dog's breakfast to fill out the forms. It was also necessary to collate information from several sites within any renal unit. This is not to blame EDTA, that's the way that it had been started, but as the numbers increased it became less and less feasible. There was an attempt then, with these digital records becoming available, to return them by modem to St. Thomas' where the EDTA Registry computer was housed. An *ad hoc* group was set up under the auspices of the BRCG, which was a joint multi-disciplinary group of clinicians, technical staff and EDTA Registry, to help that along, which it did, effectively. And this was very much facilitated by CCL, although there was no additional financial resource, as far as I know, ever put to it.

One of the come-ons was that EDTA Registry were in a position, at some juncture and by some means, to actually backfill the databases. So they would provide data, historical data that they held, audited from previous returns, to the units that were starting up with CCL. This was an incentive for the units to co-operate. EDTA Registry also started to send back reports on missing data, which was obviously variable unit by unit. There was a linear growth in the number of UK units reporting to the EDTA Registry over each of those years from 1983 to 1987, which ultimately involved two dozen renal units.

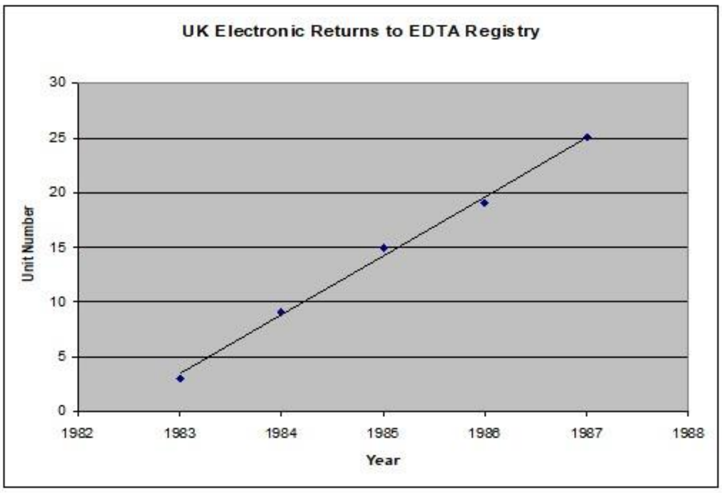

Figure 7: UK Electronic returns to the EDTA Registry

This was from the start a core activity of the BRCG, and I think probably is the most impressive example of any coherence that was encouraged in the system.

It's worth then rehearsing other successes that the group might be said to have been partly responsible for. There's no doubt that the national meetings were a showcase for computer-related activity, both centre activity and clinical activity, and inevitably there was an IT educational focus for everybody in those meetings.

It also, because there was parallel development in clinical practice, acted as an introduction, as Nick will mention in a moment, to technical advances that involved computation.[41] I'm thinking here of routine Kt/V programs and audit, which nearly became the first IT-based UK multi-centre study, but it didn't quite come off. Clearly clinicians became familiar with the computing at the clinical level across a wide spectrum, and there was a rehearsal of what would become a future development of IT within the units. The extent to which that may be said to have presaged the UK Registry, obviously, is a moot point. So as far as I can see, these were the general consequences of the BRCG activity. We shall come on later to some incidentals about why that couldn't be, and wasn't, sustained.

I mentioned UK urea kinetic modelling and that Frank Gotch had come across for one meeting.[42] We did present that with him and obviously it was a current topic, which was of interest. But even he sensed that UK nephrologists might be somewhat ambivalent about it, which turned out to be the case for various reasons. On the other hand, the Department of Health was particularly interested, once they were approached, in taking the modelling further because it was a potentially important dimension of planning renal services. What was the suitable dialysis dose and how often it should be delivered was key to the financial settlements that they were looking forward to. A small group was put together to approach them for funds to see if we could put urea kinetic modelling into a

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[41] See page 57.

[42] See page 50.

routine IT package within the most common clinical system, which was CCL, and a collaboration developed with Newcastle, using Nick Hoenich's expertise in that topic. Nick, do you want to say a few words about that?

Hoenich: Yes, just very briefly. In the mid 1980s, two things came together. The National Cooperative Dialysis Study (NCDS) study was reanalysed by Gotch and Sargent.[43] The NCDS was an American study that looked at delivered dose of dialysis expressed as Kt/V and outcomes. This showed that below a certain level of delivered dose the outcomes deteriorated. This led to the concept of adequate dialysis. At around the same time, in the UK the Department of Health was interested in resource allocation. There were still a number of units in the UK that were only dialysing twice weekly compared to three times weekly, and the question was, were those patients worse off than three times weekly? In other words, did we need to dialyse three times weekly or would a twice-weekly regimen lead to inadequate dose? Based on this, the Department of Health proposed funds for a prospective clinical trial comparing three times-weekly versus twice-weekly dialysis, which proved impossible to do. We retrospectively analysed some data that came from Mollie McGeown in Belfast, some of our own data, and some of the data from Leeds St James's, in terms of pre- and post-dialysis urea levels and other biochemical parameters, and found that there really wasn't a great deal of difference between the two.

People weren't really persuaded to stop dialysing patients three times a week and switch to two times a week, and I think that the theme rather switched somewhat to look to see whether we can, out of the data that was already being collected, have a look at what the doses of dialysis delivered were and to superimpose these on the findings of the NCDS study. A prospective study was set up funded by the Department of Health, which involved Newcastle, Leeds St James's, and I think it went to two other centres as well. The study took data that was already there, e.g. predialysis weight, blood flows during dialysis, post dialysis weight, and devised an approach to enable Kt/V to be established and monitored sequentially or

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[43] Gotch and Sargent (1985).

serially over large groups of patients in multiple units. Within this study the data collection was organised in Newcastle by a Research Associate (Rob Goodall) with support from CCL who used the data generated to develop an iterative Urea Kinetic Module with this being undertaken by a programmer at CCL (Richard Reed). With the availability of the module, it was used over an extended period (three years – the duration of the Research Associate appointment) in four different units, and it formed the precursor of what we see in terms of either Urea Reduction Ratio (URR) or Kt/V from the Renal Registry today.

Will: This was again a form of collaborative audit, but because the prospective data relied on reliable programming it was difficult to achieve. In the event, to produce a database that could come up with data sets that produced the iterative calculation from all the values that had to be collated proved really very difficult and it's fair to say it wasn't achieved. We had thought it was going to be somewhat easier than it was. But we did get data and it was interesting that Kt/Vs being delivered in units that thought they were doing fairly well in the mid-1980s was something like a mean of 0.6 (as compared to 1.2, for example) so these were rather lower than consensus values today. The other comment about the Department was that there was an attempt to do it formally and more widely in an RCT. Unfortunately, an informal survey of renal units suggested that there simply wasn't the reserve capacity to be able to allocate people prospectively to haemodialysis twice or three times a week. It would have been nice to be able to put out the results of this in print but it was based just on an informal survey. So the initiative was a casualty of piecemeal funding, the evolving funding of treatments; in the NHS you get funding after you've done the job, or after you've proven that you need to do the job.

Hoenich: I think it also highlighted the difficulty of population-based studies that require fairly accurate record keeping, which you know with the best will in the world when you're running a busy dialysis unit, somebody forgets something to be recorded on that particular dialysis but remembers it the next dialysis session, is not really conducive to that approach. Subsequently, by the 1990s this type of modelling lost favour and moved to the population-based derivative models in which a formula for Kt/V is derived by multivariate mathematical models based on a large number of patients.[44] This approach requires less detailed data input, which could be achieved on a monthly, rather than on a sessional, basis. Such an approach has become widely used, but there are still difficulties in implementing it in a large renal unit, consequently a simpler approach – the Urea Reduction ratio – (URR) is used. This provides a basic level of information about the delivery of the dose of treatment but is subject to caveats: it fails to take into account solute removal through convection, and it does not take into account the contribution from any patient residual renal function.

Will: Well, of course, this is a tail on a very large dog that we can't possibly explore, but Frank Gotch's immediate response after his presentations was that people seemed unconvinced about this and subsequent publications and other work in the UK showed some reasons why.[45] But Francis, I'm interested in the US reaction, because the people, the pundits in the US, denigrated the URR for the sort of reasons that Nick has spoken about, but had they gone on with Kt/V, using iterative computational methods, per case or as blocks within unit systems? What had the big dialysis chains done about this?

Dumler: The whole situation in the US is entirely different to here, although I think here in a few years you will be the same. Initially, we were part of the NCDS study, so it was a very rigorous study. When we had our patients randomised they were in a separate area of the dialysis unit, the staffing ratio was double what it was before, and everything was done very well but not like in the real world. But the data came in, since we had done it and we were doing the calculations themselves we went ahead and did it the regular way. The biggest difficulty was the residual renal function, which plays a huge role when you're talking about twice a week and three times a week. In the study the patients were motivated, so they collected every single drop over three days and there it came. But for the other routine patients, I mean it could not really happen.

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[44] See Daugirdas, Depner, Gotch, Greene *et al* (1997).
[45] For example, Stein and Walls (1994).

Will: It was logistically demanding and complicated.

Dumler: We had to have estimates of it and after a while we had a conversation and said: ‘You know, let’s do it this way.’ At that time, I had no knowledge that over-dialysis was particularly harmful, except for being hypotensive all the time and things like this. So we said: ‘Forget the residual clearance, our job is to provide the minimum requirements for the machine. If they have residual renal function, then they’re going to get extra clearance.’ Now clinically in part you could tell: a patient who started dialysis three months ago and only gains 1kg; another guy next to that station is on dialysis three years and gains 4kg. There are two choices: one is very compliant, the other one is not, or this guy is not very compliant but he pees a litre a day and that makes the difference. So that went out and we were still doing the Urea Kinetics. Gary Zasuwa was really a computer guru –

Will: We liaised with him at the time.

Dumler: He had written a urea kinetics program and he was an Apple developer and he sold that program to practically every dialysis system in the Detroit metropolitan area. John Sargent, who worked with Frank Gotch, also did the same thing but he had a very hard time selling his program. And one day he said: ‘Oh, what I need to do is make a billing program and it has an appendix that is urea kinetic modelling’ and every developer that sold urea kinetic modelling programs sold the financial and building programs for the dialysis unit. So that’s the first phase. A few moderate sized units developed their own system. We move a few years and 95 percent of the dialysis unit are owned by DaVita or by Fresenius. As soon as it started growing, I mean it is like McDonalds. This is what my colleagues tell me that go to different units. Everything runs the same, using the same systems, and so they develop a proprietary laboratory analysis system and the urea kinetic modelling is just a small part. When you go to see the patient, they print out for you all the calcium, phosphorous, all the things that are relevant, it highlights the ones that are not normal, the print from the previous time, and there is the model. So it’s their own system. Fresenius has their own.

Will: And is that based on iterative mathematics?

Dumler: It is based on mathematics because it makes it a lot simpler. Now, if you wanted to compare it to the three-point model, it's not very complicated. You take the, let's say the Pre and Post Urea, and then a week later or two weeks later you take just a Pre, and then you run the computer and you make it iterate until it ends up with only one result for that second Pre BUN. And then you get the volume, you get the whole works, if you want to do it that way. But in general, the practical thing is to use the mathematical model.[46]

Will: So this was offline to start with and has now become more routine from the data that are collected at dialysis?

Dumler: Right. Even before the government was requiring things, they wanted to know, and they have very smart people watching what is going on for a very simple reason: if you are under-dialysed or something is not right and you end up in the hospital, guess what? There is an empty chair. An empty chair means X number of dollars. And they are like grocery stores. You know, the margins are very thin so everything counts and so it's interesting that from the accountant's perspective, from the business people that are running the system, you end up with a support programme that is trying to keep those patients coming to that chair every single time. And so you get a lot of quality metrics.

Will: Well, that was a failed UK attempt at coherence in the event, but for good reasons beyond the control of the BRCG. In the case in kinetic modelling it was in the end a practical and time-related issue.

In the case of the EDTA returns, it was the EDTA registry itself couldn't sustain the exercises that they had generated. That all ultimately had to change in character, although the history of that change, as far as I know, hasn't been examined exhaustively. Neville Selwood had again been involved in that.

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[46] Sternby and Daugirdas (2015).

Coming back to the BRCG activities, the other thing that one should mention was renal unit staff support, because from the very beginning there was an issue about the people who put the data into the databases and maintained the computers. Those people were co-opted from all sorts of occupations within the unit environment and their grading and reward and categorisation ultimately needed to be resolved because they were effectively homeless within an NHS bureaucracy. Each hospital seemed to approach that problem slightly differently and the people were not given uniform job descriptions or anything like that. Right from the beginning there was an NHS problem with those staff. The BRCG put together a survey, trying to work out what was the problem here, just how complicated was it, and Barbara you were involved in setting that up and got responses from colleagues. You yourself were in a predicament like that. Could you describe where you came from into the Liverpool set up?

Mrs Barbara Temple: Yes. I was interviewed for a full-time ward clerk post and when I arrived on the Transplant Unit on the Monday morning, somebody said: 'Oh, Mr Sells, the consultant, would like to speak to you.'

Sells: Would you like me to leave the room, now? [Laughter]

Temple: So when I went to his office he said: 'Well, I need to talk to you about what we want you to do on the Unit.' So I said: 'Yes.' He said: 'We've got a little computer.' And I sort of looked at him and he said: 'So we want you to run it for us.' [Laughter] 'But I've never seen a computer.' And he looked me in the eye and said: 'Well, are you game – to give it a go?' [Laughter] And I said: 'Yes, okay. I'll give it a go.' And I have to say that Geoff Taylor was a very, very big support to me at the time. And I've had a look again through the BRCG survey form that you sent on and tried to answer it from my own experience, if you like.

Will: I should say that we put out a paper survey, which was on two sides of A4 about the status of the people involved, their grading, their rewards and so on, in order to get a picture nationally of what was happening.[47]

Temple: I think probably people in other units who had similar situations to mine, were working on the Unit and somebody said: 'Would you like to take this job on?', with no idea at all what they were really letting themselves in for. They were mostly clerical staff; some were part-time and some were full-time. I think probably the part-time staff had to get another part-time member of staff to help them because as things grew and the data input grew, it was definitely a full-time job. There was no training at all; you sort of learned as you went along. I should think probably in most units there was a doctor who would stand behind you and help you out if you were in need of help. There was a huge amount of data to be input but when the survey was done, that was 1985, a lot of that had already been dealt with, certainly with units who had got their CCL systems earlier. By that time, we were very lucky at the Royal Liverpool because we were getting downloads of data from the labs. There was absolutely no (local) hardware or software support; we had to depend on remote support from CCL and from, I think the name of the firm was Clinical Data Systems in Derby. They would either sort it out over the phone or they would send an engineer up from Derby to sort us out. But that was the only support that we had.

Will: It was characteristic at the time, I think, that IT departments in the hospital were much more involved in hardware, data transmission, and that kind of thing rather than software. And I think everywhere was slightly different depending on the intuition and interests of the locals.

Sells: They were dead against it. They were little Hitlers, but I'm sure Barbara will dilate on that subject.

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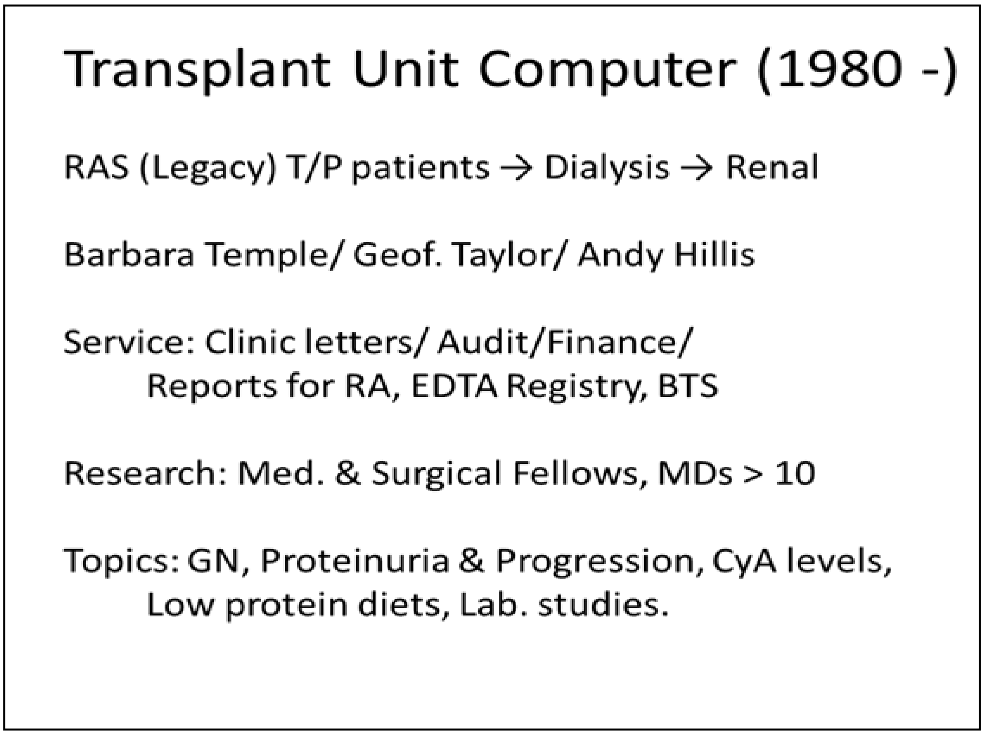
[47] See Appendix 4.

Temple: Yes. We went down to Charing Cross, Geoff Taylor came with us, and I think you were there as well, Mike (Bone), to see the system demonstrated, because it was very obvious to me, who knew absolutely nothing about it, that after a few months with the system that we started with, it was totally inadequate and we were really, in a way, wasting our time. Geoff Taylor, I think it was, went down to Charing Cross and came back full of enthusiasm. So we went down to Charing Cross and saw it demonstrated to us and a couple of days later, Robert said: 'Well, I think, you know, we've decided we are going to buy this system.' And I said: 'Oh, that was a very quick decision. What made you decide so quickly?' And he said: 'Your face, when they were demonstrating what they could do. You know, because you're so frustrated with what we're doing at the moment.' And, as our knowledge grew, and our data storage grew, we depended greatly, well totally really, on the training sessions that CCL provided. Those cost money, which again, the hospitals weren't the slightest bit interested in funding. So every time Mike had to find some money, or Robert had to find some money, for us to go to these sessions to learn. And I have to congratulate CCL that I thought their support was superb and their training sessions were excellent.

They were dealing mostly with clerical staff and they didn't blind us with science; they talked down to our level so that we could understand them. And people became very, very enthusiastic about it. As the staff became more experienced in what they were doing, they decided amongst themselves really, in each hospital, that they needed to be upgraded because they were doing an awful lot of things that other clerical officers weren't expected to do. Well, there again the hospitals weren't in the slightest bit interested in looking at gradings or providing job descriptions or, they just didn't want to know. I think that's true – they just didn't want to know. And I think the thing that saved a lot of units was that people, by this time, had become so happy with the system and liked what they were doing with it, that they were prepared to carry on and leave the upgrading message, to be taken to the hospitals, with the clinical staff, with the directors of the units. Eventually it did start to come through but it was very, very slowly and very begrudged, I have to say that, but I think they realised that they had to do this because we were such a small community that if you started to lose staff, you'd have to start all over again, or you’d have to employ staff who were computer trained, to come into these posts. So the upgrade was there anyway.

By 1985, we had really developed the system. We were not only storing data and the clinicians were using it, but it was also being used by the nursing staff to help them in clinics. We had a lot of things going for us, and it was suggested, and I don’t know by whom, that we should go over to Boston and demonstrate the system to renal physicians in Massachusetts General. I don’t know what the outcome of that was but we had a lovely visit to Boston. [Laughter]



Transplant Unit Computer (1980 -)

RAS (Legacy) T/P patients → Dialysis → Renal

Barbara Temple/ Geof. Taylor/ Andy Hillis

Service: Clinic letters/ Audit/Finance/
Reports for RA, EDTA Registry, BTS

Research: Med. & Surgical Fellows, MDs > 10

Topics: GN, Proteinuria & Progression, CyA levels,
Low protein diets, Lab. studies.

Figure 8: The Liverpool Renal Unit (supplied by Professor Mike Bone)

Will: It is true to say that initially the activity was data entry but actually these roles evolved into much more complicated computer support arrangements in terms of maintenance, in terms of shepherding, if you like, the databases and being constantly on the watch for what needed to be changed, and so on, and so forth. Is that fair?

Temple: Yes.

Will: The posts became really quite variable in each unit. In the end there was a designation of 'computer manager', or some other managerial term crept in, to try to convey the fact that this is a much more complicated role than simply data entry. Early on this was not necessarily the case because most of the personnel came from what Clay Sherky has called a 'cognitive surplus'.[48] In other words, that there was a surplus of suitable clerical capacity in some of the units which could be applied to the computer. People were also taken off other roles – data logging and so on. I remember a discussion with Terry early on, about the economies of all of this – what you actually needed to run systems like this.

Was it inevitable that you needed dedicated staff? Was it inevitable they would have to have certain training and so on, and how would that be brought round and afforded? It was all outside existing NHS categories, that was the problem. Is that fair, Terry?

Feest: Yes, I mean we had no staff for it in Exeter. We had a ward clerk who put data in. I suppose I was the computer manager, along with a lot of other early enthusiasts. I wasn't much of a manager; it meant a lot of phone calls to CCL if anything went wrong. [Laughter]

Will: This was unassigned and unrewarded, and completely outwith the clinical role, this was in addition to, this was being a 'clinical information officer', just as part of what you did in everyday circumstances, and this was over and above your necessary commitments.

Feest: It was part of the problem of being one of the first specialties to get involved in this kind of application. Obviously as hospitals began to look at all sorts of other

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[48] Shirky (2010).

IT applications, then roles became established, but we were trying to establish a role before anyone else was interested.

Will: And that went on for a very long time. [Laughter] When you moved to Bristol, I think there was quite a clear computer support staff, is that right?

Feest: No.

Will: You weren't doing it. Was there not a data manager / computer manager in Bristol in the end?

Feest: There was in the end, not when I moved to Bristol. Again, in Bristol it was being managed by an associate specialist who was extremely keen and very competent, more than competent. Then he retired and at that point we managed to raise the funds to appoint someone with some IT knowledge to manage the system.

Will: Andy, do you want to have a word?

Dr Andy Stein: I'm a consultant in Coventry, which is a medium-sized unit that still uses CCL Proton. I will give you an update to the modern age. So most units of our size have three or more data input clerks and these are sought-after jobs by other clinic clerks or receptionists, whenever they become available. And most units our size have an IT manager, which we do. So we're lucky in that way. We also have a consultant, who is our IT lead, Dan Ford, who many of you will know. So consultants now get jobs based on their IT skills, which I don't think perhaps was the case in the day when many of you were junior nephrologists. The other thing that does continue, is the battle against the hospital, because inevitably the IT lead and the IT manager are battling with the entire (hospital) IT department regarding developing IT systems. And the usual answer is 'no' and when you say 'why?' they say: 'Because we're about to set up the world's best electronic complete patient record.' [Laughter]

Now, I was told 17 years ago when I became a consultant that that was going to happen within 5 years, and they are still saying that; and that is still used as the reason for the Trust (as a whole) not to be as interested as it could be in the development of renal systems.

Will: I'm sensitive to the idea that the Agenda for Change skittled all this because there were no categories that really related to the need for development and maintenance of these systems, and because the institutions have moved towards generic roles, generally speaking. There was a clear out of people with specialty experience. That's not the way the system was designed to work. So there were several things downstream, which in an ideological way overturned it. It's interesting, Andy, that you said 'lucky' because it sounds as though you feel you may be exceptional and that everybody else has got structural problems about how to deal with this. I see Peter Rowe here nodding.

Dr Peter Rowe: I was just thinking Andy, you are very lucky. We have had no systems manager or data input clerk for about five years, as a cost improvement. We took on the role ourselves, the clinicians did it and the nursing staff, and a bit was devolved to the relevant nursing managers and to individual teams, the transplant stuff goes to one of the transplant nurse specialists etc. etc. And, as a result, it's given less good quality, I would say, and when you said your Trust's response is always 'we're going to do something much better which will do this job for you', we get the exact same response to requests for support to develop our own information system.

Will: So this has come full circle in a way. What interests me is the fact that we are all engaged personally day to day in these kinds of IT activities anyway, with our smart phones, iPads, and our laptops. It has been latterly less of a step for consultants and others to become directly involved in this kind of activity, because we are used to doing it, whereas originally it was a very big step indeed. In the US for example, the time demands of data entry have become such that it's widely felt that it's demoralising those in consultative practice. They are employing, and are now establishing in a formal way, ‘scribes’ to enter data on which clinicians shouldn’t be using their time.[49]

Rowe: The one thing that is changing, the driver for actually improving data quality now is nothing to do with clinical or computational purity, it’s purely financial. And now the Trust has realised it can increase income by getting its coding more accurate, it’s decided to put some resources into using IT systems that actually describe clinical activity in a way that makes it useful for business partners, as they are now called.

Bone: Can I ask Barbara? I have the impression that, maybe in the later 1990s, x-ray was getting fed directly, pathology was getting fed directly, into the written form. Is that true?

Temple: Yes.

Bone: And did it stop?

Temple: I don’t know.

Sells: It’s still going. Well, we set that up in 1985 and it’s been going ever since.

Bone: So that hasn’t been interrupted?

Sells: Radiology had this huge revolution now they’ve done away with all the jelly and silver salts and you can get your barium x-ray that you had last week in Somerset, electronically up to Liverpool..

Will: It has a bearing on the issue of capturing the *status quo*, without really being able to explain it. So the simplest thing is to capture the data. Exactly why it’s like that, why one number is different from another needs additional information.

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[49] Miller, Howley and McGuire (2016).

Entering items like prescribing information is inevitably more complicated than a laboratory download, and so people have tended to concentrate on the givens, the French would say *donnés*, the lab stuff comes at you and you deal with it, plausibly and for good reason. But nevertheless, it potentially diverts attention from the much more difficult problems of clinical data capture. Terry, would you comment on that? Is there a difference between the completeness and accuracy of data derived from different sources when you come to look at it collectively?

Feest: It depends how you set it up. You have to set up the computers to be useful for clinicians, I think that's the secret. In Southmead we don't have data entry clerks, and I don't think we need them because all the members of the team use the computer as part of their daily routine. It's where they look up information and record what they've done as they go. In terms of prescribing, we had a prescribing system that actually only worked for outpatients because it was useful to clinicians. We put the drug prescription on the Proton system, you could record allergies and that it would note that. When the outpatient wants a prescription, you press the button and the prescription rolls off for you to sign. Now that saves the clinician quite a lot of time and it eases their agitation when they make a drug change and have to put it into the computer. If you record the drug on the computer and for the next 20 prescriptions you press a button, off it comes, and all you do is put your signature to the paper, then it's quite a good thing for you to keep the computer record up to date. You don't have to persuade people quite so hard. So structure is important, you know, if we were asking clinicians to record the drugs and they still have to write them out for a prescription, well why the hell should they bother with the IT? I think you have to make the thing useful.[50]

Similarly, we had screens for dieticians so that they have their own screens and this is what they look up, and when they make a change they record it and they've got it next time. Nearly all our clinical groups had a similar facility.

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[50] See further similar comments by Professor Terry Feest on pages 80–81.

Will: But it comes back to individual unit preoccupations, interest, capacities, infrastructure, history.

Feest: Well, I think that's a basic principle. I would ask another question: if you're putting data in that people find tedious to put in and see no value in, why are you asking them to put it in in the first place? [Laughter] Well, that's not a joke, that's important. That's the whole point – if you don't have that attitude, it won't work.

Gordon: I would imagine that some of these political issues that have been spoken about, might explain something and that is that I've noticed, as time's gone on, that GPs have systems which seem to be doing a lot of the things that we struggled to do. And presumably that's because I think they have some degree of independence in how they run the practice, that's my recollection – our practice presses a button and they can generally look up what's gone on. But data input was a very interesting problem, and the way that we did it finally, I borrowed this idea from MIT from a project they were doing for the Defence Department in the States, no less. It was called Spatial Data Input, and it had a large screen and the concept was that if you had a picture of the things that might be on your desk in different heaps, you could point to that with a device, like a mouse, there was a whooshing noise, and you went through the screen into another data space. It was great. And there you could look up whatever it was you had in that pile of papers. I explained this to Conrad who adapted it to use the key pad as a data 'map', which proved more efficient than the mouse. But it was certainly difficult earlier on. I remember we had somebody for a short time to help with data input. She came from a department that was doing skin transplants, and she entered lots of data in one day, and something wasn't quite right. She came back and the data had gone. And she said: 'Oh, it hasn't taken.' [laughter]

Temple: Can I just say, Es, by 1985, we were not only using the computer on the Transplant Unit and the Renal Unit at the Royal Liverpool Hospital, and the Isle of Man, but also in our contributing hospitals in North Wales.

Will: Thank you. In this third section we've used the title 'contributions' and we particularly put down the CCL element. Now, we spoke earlier about the aspirations for coherent development of the BRCG, I pointed out that the EDTA returns at least and some other things demonstrated the utility of some coherence. In retrospect we might argue, we could discuss the fact, that the coherence that was really required was largely related to CCL and the software. One of the giveaways is that at the first meeting of the BRCG there was convened a so-called CCL User Group meeting, which 'took advantage of people getting together'. The CCL User Group and the BCRG became intertwined over the whole period and subsequently. One need not apologise for some focus on CCL, because that was clearly the national clinical software leader at the time. Perhaps one of the amazing things we may register is that all of that still keeps going. The renal units are still sending in large blocks of material that are suitably arranged to the UK Renal Registry, although I wouldn't know what proportion are now CCL units but obviously it remains considerable. Is it something like half?

Feest: Less than half.

Will: OK, less than half. Of course, this development was asymmetrical, because some centres, either through enthusiasm and interest in their senior staff, or the enablement or collaboration with other people, developed a good deal more than others. The centres became somewhat different, in that some were developed across a very wide range of functionality and others not. We have mentioned already some of the things that led to renal units becoming so suitable for this kind of IT activity, the initiative of semi-academic clinicians, their capacity to improvise, and the leadership that they took about unit development. There was a feeling of more or less complete engagement of clinicians, be it physicians or surgeons, at that time in the development of these systems. Others have pointed out that the nephrological need was characteristic. Not only was it information intense but that information was largely numerical and it was serial, which obviously offered itself to a computer solution. Not only that, there were few major treatments and those treatments were complicated enough to benefit from registration and follow up in their own right, as indicated by commercial interest.

It’s incidental, but perhaps not without importance, that the paper records by the early 1980s were becoming gargantuan, because maintenance dialysis had been going on for something over ten years and there were patients to whom a great deal had occurred. There were initiatives in the problem oriented direction, I know Mike Goggin was interested in Dr Weed in the US. But those sorts of things only partially addressed access to useful clinical material.[51] So not only were the data suitable for computer registration and manipulation but there was also a problem with the sheer amount of it. Another striking element is that this was a period of austerity, in the modern sense. The austerity was in senior staff numbers. Most of the units by the early 1980s might have had one or two nephrologists but not much more than that, and there was a lot of work done by delegated registrars, who were wonderfully skilful, but obviously assumed different roles in the strategy of patient management. There were national manpower surveys and there was soul-searching about professional development and so on.[52] But with a caseload that was rising by 6 to 8 percent or more every year, there had to be some way of managing this. It is hard to avoid the feeling that austerity in senior staff numbers was another incentive to try to deal with the data, and to manage them rather better.

As an aside, there is modern theory about why IT systems are successful and Trish Greenhalgh, in particular, with colleagues, has talked about socio-technical solutions, that systems work for a combination of technical and social reasons.[53] One of the interesting features is the size of the staffs of renal units, because Robin Dunbar has pointed out that the human brain can be closely related to, or intimate with, perhaps up to 150 others but beyond that it starts to get difficult.[54] When you think of the size of renal units, they actually correspond to the size of the social units that the human brain is well adapted to deal with. So a socio-technical explanation is actually quite plausible in the setting of renal unit.

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[51] See page 14 and note10.

[52] Jones, Goodwin and Roberts (1984).

[53] Greenhalgh (2016); Greenhalgh and Stones (2010); see also Clegg (2007).

[54] Dunbar (2010).

These were some of the background features to the survival and development of the CCL project. Keith, we thought you might start us off on discussing the scope of unit IT. Your ambitions were relatively unlimited, I think. I'm not sure what phrase would encompass the intentions.

Dr Keith Simpson: Well, I suppose I first met computers as an undergraduate where I inhabited the Physiology Department. We were very lucky that the professor had worked with the Nobel Prize winner in neuromuscular transmission, and as part of their work had bought one of the very powerful PDP computers that my friend Conrad referred to. I can't remember if it was 1969 or 1970 but we would just get free rein of this thing and were allowed to play with it, basically. It's quite humbling to hear that you (Conrad and Mike) had to run an emulator on a mainframe, and only a lot later, got access to this same machine. So, during my undergraduate career, I was aware that computers could do clever things, quite powerful things, in real time and they hadn't really been applied to medicine. Indeed, in my undergraduate clinical years I was struck by the almost complete chaos that surrounded us.

It's not something that we've talked about really. It was just utterly chaotic, yet it was managed by really clever and able people, who seemed, as we have said, to just make it up as they went along and solved all the problems and they obviously enjoyed doing that. So I thought: 'What is the key job of a physician, as opposed to say a surgeon or nurse? What's the job of the physician?' And it seemed the key thing is collecting the data from the history and investigations, merging with the literature and making a diagnosis. Almost everything else can be and is now done by somebody else. Making the diagnosis is the key thing that the physician has to do. The tools to help us do that, to collect the data, to get access to the literature, the evidence, are computers.

The big question I'd like to ask is, why on earth have we physicians in general (I was very lucky, my colleagues were very enthusiastic about this) failed to use computers in almost any aspect of our practice? Some of us have refused to use them and some have actively worked to stymie the introduction of computer technology in medicine. Why is that? What is it about these things that is so intimidating that some would prefer to continue muddling along making up their own rules, and failing to use tools that can demonstrably improve safety for our patients? We don't do that anywhere else. Do you remember the adverts for Qantas Airlines that said it was the safest airline in the world, and they sold lots of tickets on that basis? Volvo, not the fastest, not the smartest, not the cheapest car in the world, but they sold them on the basis of safety. And we bought them in the hundreds of thousands and millions. Yet in medicine, it seemed at that point physicians were not trying to grab tools that could help them to work more effectively, more efficiently, and more safely, and I wonder why that was?

When I went into renal medicine as an SHO I was told by my boss about the Belfast effect that Mollie McGeown and her colleagues had described and the apparent advantage for transplant survival in patients who had received a blood transfusion. So my task was to go through the notes of all the patients in the renal unit, and pull out those who had been transfused and who had not. That was pretty tedious and at that point I thought: 'We really have to get into computers in medicine.'

I was very lucky, there were quite a lot of computer systems and database applications around and in renal medicine we were lucky that we had the CCL system. I know it wasn't all luck but having developed this incredible system with remarkably few resources in terms of the computing power that was available and to produce such a phenomenally useful system, it was lucky that we all heard about it relatively quickly and pretty well all used the same system. Adoption of standard systems is nowadays actually quite unusual.

What subsequently happened in the Tony Blair era was that huge IT companies sent their programmers into warehouses to write code, but they never talked to any clinicians. What we had in renal medicine was the complete opposite. We had regular discussions between clinicians and computer experts, which worked incredibly well, which is why we're all here today. I remember Mike (Gordon) telling me that he and Conrad had discussed this problem very early on in their association and had recognised that it was probably easier to teach willing physicians a little bit about computers and how to enable the computer, not necessarily to program them but to set them up and use them in their work; it was probably easier and better to do that than to try to teach computer experts a little bit of medicine. I think that's what a lot of the other systems have tried to do. They tried to get their computer experts to imagine that they knew enough about medicine to produce useful systems. As we know, mostly that has failed.

So we got the CCL system. Within a week we had lab results coming through, which is pretty good when you look at modern developments where it can take years to do that. You will all have had a similar experience. Jim Glover from CCL came to work with us, and within a few days he had set up the system and we had lab results. Then we adopted what was almost a unit policy, that when we could do something on the computer and wanted to do it on the computer, we got rid of the paper. Everybody accepted that it was their job to put in their data on this electronic record and to record it for everybody to use. So the physicians had to put in the diagnosis, not anywhere else, and had to put in the drug prescriptions. Similarly, the nurses did the blood pressure, the urine testing, the clerk, the secretary did the letters, and that's how it evolved.

Will: There isn't a name for the processes that they all undertook, in the sense that you had to describe, you had to go through, the whole list of who had the responsibility for what, all of which is entirely legitimate. But again, Trish Greenhalgh came up with the notion that each functional group has a series of what she called routines, and gave a name to the fact that everybody knew that X would enter Y, that was their job.[55] From the outside it wasn't apparent, and it might not be written down anywhere, but unless you have a term for what you described, you can't really convey it particularly well. What you have described is

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[55] Greenhalgh (2008), reply (letter) Will (2008); Swinglehurst, Greenhalgh, Myall and Russel (2010).

a series of semi-formal routines within a unit that allowed everybody to come up with a comprehensive data entry methodology. It's absolutely no criticism, you understand, I'm just trying to find a word for the activity.

Simpson: I don't think those routines were dependent on having the electronic record; I think they existed already. I think the distribution of work in renal units is different in each unit. Some functions are done by one professional group in one, and in a different way in another. The point was that we were all generating information and we tried to get people to stop writing it down and just put it in the computer. As far as the paper returns to the department (like lab reports) were concerned, we just stopped using them.

Will: Yes, early on the paper routines were replicated in an IT environment. In other words, what had happened before was converted into a more or less equivalent model but in an IT environment. Is that correct? That's what others have noticed. The intuition when you are given these tools is to actually replicate what you already do, so is that a fair comment?

Simpson: Yes, and you're collecting lab data, you're collecting symptoms and diagnosis, and recording treatments. Other things evolved from there and the way we did that was by taking little steps and trying new things and failing many times but not following up the failures, or changing what we did and then try something else. It was an iterative process of small trials, experiments if you like, they weren't properly controlled, but we recognised that some things were fine and some things weren't.

Will: When you say 'we', was that you personally leading the continuing innovative effort, to use the modern word for what we're talking about, that there was some pressure to see what would work?

Simpson: Yes, and, actually no. Within a big department you play to people's expertise. So there were people who were experts in, and keen on, transplantation, PD, whatever, and each of them would come up with something that they wanted to do. As long as it was within the department, the renal unit, generally we could get on with it. If it involved collaboration with hospital management or the IT department in the hospital, I have to say, it usually failed because there was no incentive, no imperative and no apparent benefit to them for doing it. They refused to accept it. A nice example: we adopted Read codes for the diagnosis, which could be translated into ICD (International Classification of Diseases) codes, so all the letters including discharge letters, would have Read coded diagnoses from which you could immediately generate the ICD codes from which the hospital would be paid. We said: 'Do you want us just to cut out the paper and send you the data electronically?' No. They wanted us to print out the paper, send it to them, they would then look them up in the books and, they found it relatively easy because the text was the same, look up the code and submit the entry into the patient's national returns (SMR1).

Will: Drawing back from the interface with the bureaucracy, was it you that would vet the fact that somebody in another area of the department wanted to do something, add some function to the activity? I'm just interested to know what the dynamics were, because you can't have allowed a lot of people to do their own thing at any given moment. There had to be some kind of integration of effort?

Simpson: I suppose it was me and the data manager, the computer manager, who felt exactly the way Barbara described: coming from a background of medical secretarial work, and became incredibly expert at running the system and writing enquiries using the Quark system, or exporting data to statistical packages and analysing it there. It was amazing what they learnt to do.[56]

Will: Can you give examples of where this didn't work, within the unit? We talked about UKM and that being rather difficult to do. Were there routines within a normal clinical environment that really resisted transfer, replication in an IT setting? I know you talked in your paper about the 'anatomy' of a nearly paperless unit.[57]

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[56] See comments by Mrs Barbara Temple on page 63–65.

[57] Simpson and Gordon (1998).

Simpson: I can give you an example of a nice development, which was blocked, but it didn't fail at the clinical level. That was the problem of medicine reconciliation. When a patient is admitted you've got to try to work out what drugs you think they're on, what they think they're on, and what the family doctor thinks they're on. Then, having sorted that out, you convert it into a hospital Kardex, which unlike the prescription that the patient has at home that says 'take this drug three times a day', the Kardex asks the nurse 'please administer this drug at these times.' So we wrote a little program that took the patient's prescription from when they came in, that they told you about. You'd record that, or you'd update and make sure your record was right, and then it would immediately be displayed in a Kardex format so that the nurse could then administer it at the times that they happen to be doing a drug round, record whether they had given it or not, you stopped those that you wanted to stop, changed the doses and so on. So you ended up with a current prescription but it was a continuous record, and when they went home again it was turned into what looked like a prescription for a GP. But that project was blocked at a high level.

Will: There was a sense in which, for something like two decades, you could almost have said there was a renal hospital within a hospital because the IT was generally speaking looking inward. The more modern emphasis on communication, multidisciplinary work, contact with primary care and so on, was much less obvious in the 1980s. Of course, latterly other solutions have had to become necessary but there was a kind of long honeymoon period where the renal clinicians were largely responsible for what happened with their patient group and had continuous supervision of them. The outside world needed to know some things but that seemed to be less critical in the development. Terry, you also did extensively a lot of what I'm calling routines. What would you say to Keith's description?

Feest: I'd agree with what Keith said. You need to get your staff on board. It depends how you start out. You talked about people duplicating what they were doing on paper on the computer. I don't look at it that way. I think the computer was the oil in the wheels that kept the unit turning over and we were trying to perform a function in terms of clinical care that the tools we had were not very good for and we were looking for new tools to do the job. We may then have taken that on. So the fact that we were duplicating paper records in the sense that we were recording the pathology etc (electronically from source, not by hand) which were also returned on forms, well we had to record it somewhere, we were recording it somewhere better. Like Keith, you don't do it in two places then. So I think there were certain principles: you didn't duplicate in the sense that you didn't make them put it in the computer and write it down. The things you tried to do that way didn't get put in the computer. As I said before, the other thing is you had to make it useful for people.

Will: Can I just interrupt you there? You didn't put it in the computer but there was a sense for most units that computing was a third-party record, because in most units it didn't actually contain the whole record. So there were free text components, early on anyway, correspondence and other continuation elements which were not IT recorded, which meant that there had to be a paper record. And when it was a third-party record, that obviously generated problems for consistency and coherence. Did you get over that in Bristol?

Feest: That's a value judgement, you see. I would have said it might have been the first-party record and the paper record was a third party. We didn't attempt to go for paperless records because if we'd done that we'd never have got started. What I think we did need to do was look and see what was useful on the computer and what was useful on paper. We didn't go around sticking all those pathology forms in the notes either – you either had it on the computer or on paper, but we weren't trying to persuade physicians that they had to sit in outpatient typing because none of us were good at that. So we did have a handwritten paper record. What we didn't want to do is duplicate that on the computer. But it's a winning situation once the computer is useful for people. I gave the example of the outpatient drugs prescriptions (which the new hospital system for prescribing has messed up a bit), but also if the drugs are recorded, you can immediately print out a record, for example when you dictated letters you never dictated the drugs because you pressed the button and out came the list of drugs to attach. You could also do that when you were passing people to other hospitals.[58]

There are all sorts of ways in which you make IT useful without duplicating people's effort. I can remember the early days in Exeter when the ward clerk was bashing a computer that wasn't working and said: 'I never knew how much I used the bloody thing, I never knew how useful it was!' and that I thought was success. You know it is the oil, it's not that people are talking about the computer, it's finding they can't do their job without it because they do it so much better with it. The other thing I agree with Keith is that you've got each department. We had dietician screens and social workers and whatever it is, they had to have their screens and that's why the CCL and Proton system was so useful, because you could develop that. They took responsibility for that, so we didn't need to have data entry clerks because people accepted responsibility for their bit of data. But it had to be useful to them. The main problem in getting good data is the human being. The stuff that comes from the laboratory, from the hospital mainframe system, there are all sorts of things, that's easy. It's when you need a human being, you have to give them an incentive of some kind. Sometimes it's force, if you can't describe any other way. There has to be a benefit otherwise they're not going to do it.

Can I just pick up one other thing? The graphs you display is one of those incentives sometimes. And the other thing is, it can look outward; we didn't use them so much latterly, but we did generate things like prescriptions for GPs. You could actually generate print outs that could be sent to GPs and we often used to include a summary of the screens we made with the GP, instead of having to dictate the summary of the patient every time. It was a useful tool for outward communication; it was often more the problem for people outside rather than people inside, that it didn't get used.

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[58] See earlier comments by Professor Terry Feest on page 70.

Will: Well, structurally one or two things got in the works, for example, when people tried to get the Erythropoietin prescribed externally, there was a sudden change in the need for information passing in two directions, and that was particularly difficult. I admire your logic about this, but my anecdote is that we had transplant coordinators for whom we created screens serving what I called a patient's 'Transplantability'. They were to use those to work up, sequentially, patients for transplantation, which they did very effectively. This ran in the live donor clinic as well and supported the expansion of live donor donations and so on. I thought this was wonderful, except that I discovered, some years later, that they had printed out every screen. Don't ask me why, and I never knew. They didn't tell me, and I don't think it was a UKTS instruction. Simply that one doesn't always know what's going on in the circumstances. People will do potentially quite illogical things.

I just want to move on to the idea of re-engineering. Last year (2016) people may know that Robert Wachter was asked to give a review of IT in the Health Service, and one of the things he promoted, although I don't think it was his idea originally, was the notion that generally-speaking clinicians will replicate what they're already doing in a new IT environment.[59] Then, as they get used to what they can do, their ambition and intention will develop and they'll re-engineer the clinical processes in some way or other. From my point of view, it was the review of satellite patients that I re-engineered, because the CCL graphics were so flexible, and the exception reporting so easy, that we could usefully change the way that we monitored satellite haemodialysis activity.

Keith, was there anything in retrospect that you re-engineered so that it didn't work in the same way, it was actually significantly different in some way?

Simpson: We accepted ward referrals from surgeons and so on. That had previously been done in the traditional way that is by a letter or a phone call to the Unit Secretary. But once we twigged what we were actually doing, the phone

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[59] Wachter (2016).

call would usually go through to the on-call registrar, who took a brief history from the surgeon and entered it in the patient's record on the computer while they were on the phone, and then put a flag on the patient record saying that they were now what we called a 'ward outlier'.[60] Then, after the consultant renal ward round each day, we would print this list of referrals (because we didn't have terminals in the other wards), read the note left by the on-call registrar, and have a list of patients we had to go and see around the hospital. That just completely transformed the way that we responded to in-house referrals from other departments within the hospital. You had a proper list of who you would go and see, you could get their biochemistry, they'd been registered on the renal system if they hadn't been before, so while the ward round was going on, all their previous biochemistry/haematology would be downloaded and we had the rather telegraphic report from the registrar who had taken the call describing what it was all about. That just transformed the way we handled ward referrals.

Will: Yes, and of course in some centres the ward round was accompanied by a terminal whereby you didn't have to retire to the coffee room in order to look at the lab results and think about what the problem might be. You could do it at the bedside. Terry, can you think of any re-engineering issues, where you moved into areas that weren't duplicated.

Feest: Well, there were just new possibilities. We didn't quite have that referral system but if we registered the patients on the renal system then automatically all their back biochemistry etc. were entered from the labs, and we could also later get that in other hospitals, from other hospitals, too. So, if I saw a patient in my clinic in Bath, I could get all the Bath data. It just slowly evolved. Isn't that inevitable? We worked the way we do before computers, because it was the best way we could see. It may not be the best way but it was the best way we could see to perform the ultimate function. We were looking for another tool to do it even better, which was the computer. The computer didn't come looking for us, for most

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[60] Dr Keith Simpson added: 'The addition of computer software that communicated with the hospital PAS and enabled the patient to be registered on the renal computer within a few seconds, at the start of the referral phone call made this possible.' Note on draft transcript, 7 October 2017.

of us we went looking for it, I think. Then when we got the tool we began to realise all these other things we could do.

Will: Exactly. Peter, coming from a unit that used CCL but didn't generally aspire to the scale of activity that we've been hearing about, do you have any thoughts about the day to day activity and the way that it fitted together?

Peter Rowe: Yes, sure. I thought I might just presage that by saying that my introduction to computing actually was by the time this period ended in 1992, when it was just being introduced. When I arrived on our Renal Unit it had a computer running. It was a PDP, that was referred to already that Terry bought. I just assumed that was business as normal, [laughter] which was very interesting. For me it became such an obvious thing to use that I spent my on-call evenings learning to play Dungeons and Dragons - for those of you who remember that game. [Laughter] So that actually emphasised something both Keith and Terry have said about people using systems they gained from. For me that was a minor gain, but the major gain was the clinical use, of course. But it actually emphasises that point. You will use a system and maybe one that actually you can game on. It's a bit like meetings; people go to meetings that they know work, they don't go to meetings that don't work. So the trick is to make people engaged and to make people gain from the way it's done, in terms of lots of examples we have heard about during the course of today.

Will: While you're on that topic, how do you get people who haven't been engaged in the development of your original systems to be motivated to use them? Because that still seems to be one of the problems.

Rowe: Well, I have two observations to make and one is that since I've been a consultant, I've actually done quite a bit of system development. One of the things to do is to make the information accessible. The renal IT story started off with a system that just recorded pathology (principally biochemistry and haematology) because the problem at the time was the volume of paper reports and trying to get access to them. It quickly developed into an embryonic patient record and since then there have been many incremental improvements and also many more IT systems introduced in other specialities. We've talked about the various aspects of the piecemeal early development today. I don't know what your Trust is like, but in ours there are about seven or eight different systems providing the routine clinical information required to assess patients on a day-to-day basis. So, what I did with our system in the last ten years was to make it accessible to all the systems, so they automatically feed into our renal system. This means you can look at all the relevant patient data on one system, and that's the renal system. Of course, this is not a complete electronic patient record (EPR). We don't record real-time patient data on our system automatically from clinical observations or clinical progress notes, but we do put diagnoses on and construct a medical timeline record, and we do generate letters from the system with prepopulated fields and store the letters in the patient record. So if you want a letter, it's on the system. If you are writing a clinic letter or a discharge letter, you dictate free text and the system generates the diagnosis, the drugs and the investigation from that admission, and adds it to the free text you started and then stores it. So, when you go to that patient's record, there is the letter with the bits and pieces on it. So those are the sort of things that make people actually use the system because the data set they require to see a patient, is all in one place.

Will: I'm inclined to ask you how big a step it was to put text from correspondence in the system, because that wasn't an early application. Obviously numerical data were a gift for these systems.

Rowe: We did it first with the Proton system we had when I went to Plymouth and we since moved away from Proton to VitalData and carried it on. And we did it originally by writing a bespoke interface in house using the usual software tools that everyone has access to. Since we had Proton, the data was generated from Proton software using templates and merged with a Word document using a Word interface. The completed letter was accessed through a hyperlink stored in Proton and was held in a separate designated network folder.

Will: You were a child of development though. Keith, do you remember the point at which correspondence went in and what difference that might have made?

Simpson: That made a huge difference. We did it before you could interface it to Word or whatever, and just did it in text in Proton. It was a bit clunky but the secretaries were very quick at typing it in. They would type it almost as quickly as they could type it on paper and we used the time saved from not re-keying the results, the next appointment, the transport arrangement, the diagnosis and drugs, to start recording the ward round notes in real time. But then the management found we were doing that and said: 'You don't need to do that, you can just write it like you used to.' [Laughter]

Will: Terry, was there a step at that point or not? Was there a step when the correspondence was added?

Feest: We didn't have correspondence on the computer when I left, but I don't know what's happened since. But there were other things – you can also analyse the data. By that I mean, I don't know whether Fergus knows this, but we would look at how we were achieving the Renal Association standards.

Will: This is after 1995 of course. It's interesting that it was.

Feest: Which consultants' patients were reaching the standards? Once you've got the data in this form you can use it in all kinds of ways and you can't analyse data if it's all on paper and notes. Even if you tabulated it into tables on paper you can't analyse it and you can't suddenly think: 'I wonder how that correlates to this and that.' So that's a secondary advantage. That isn't such an incentive to the rest – all of the staff who put data in – but it's a huge advantage to the unit. It can be an advantage in dealing with management as well. You can go to management and provide them with information they may not want to see. They may not want to know that your Haemoglobin data aren't very good and that you need more EPO or whatever. But you could also just provide them with activity data that, these days, they get money for.

Will: I was going to say 'times have changed' – it was a fruitless offering in the past.

Feest: There are all kinds of benefits you're looking for, things beyond just the sheer calculation or the data we have on paper.

Will: Peter, you were describing that you were actually brought up on some of this stuff so you didn't need motivating to use it.

Rowe: It was obvious that that was the best way to access information, so I was pondering in the course of the discussion today whether the driver for the development of IT in renal was about data access or was it about data manipulation, and I came to the conclusion that it's actually a bit of both. Because when I came to practice, the data was accessible and it was just there, so the questions might have been 'What can I do with this? How can I display it? How can I use it?' And I spent quite a bit of time trying to get data out of the system so I could use it in an easier way, because not being that good at programming, unlike some of my colleagues here, I wanted it in a format I could do something with more easily. So I spent quite a bit of time developing ways of getting the data out in a file that I could manipulate with simpler programming language and simpler systems. But I think there's a bit of both in that. And I guess that generated the development after, and I very much echo Terry's comments about the system is there, you use it and then you change the way you do things because you can see what you can do differently with a more efficient way.

Will: That's what I was trying to get at with the re-engineering but it may be that it's so gradual in terms of individual activity that it's not actually a step, it's an evolution of practice.

Feest: It's what Keith was saying: you tried lots of experiments. Some didn't work and some did, and they became part of the daily routine.

Simpson: Perhaps experiments is over-egging it a bit. We tried things. But I think it was important to try things that other people wanted, so one of my colleagues who was very keen on Peritoneal Dialysis (PD) added all sorts of equations to calculate mass transfer and transport across the peritoneum. Well you can model that and you can get very enthusiastic about that. Some things worked.

Will: I failed in trying to digitise anti-coagulation feedback. I found that if the people weren't at the end of the phone, what did you do, and how did you delegate that, and how did you not end up with a lot of loops of incomplete action? So there are some topics, and that was an external issue to the unit, which are much more difficult to complete. Robert.

Sells: As the complexity of transplant immunosuppression grew from what sounds very simple, from two mainstay drugs up until 1979, to about six now, which are in common use: Cyclosporine, Tacrolimus, Mycophenolate Mofetil, (which is probably the most influential in terms of improving results and reducing toxicity) and Sirolimus, and a couple of new agents that are being evaluated, mainly in America. Then there was monoclonal induction therapy and then we have prophylaxis, against cytomegalovirus infection, which for ten years was enormously important. My point is that what was almost a black and white situation – too much Imuran: white cell count falls, platelets fall, bleeding, infected patient. Now there are probably 20 or 30 more clinically important variables, which may be beyond the storage capacity of the system. The next big step forward will I think be a discharge summary with a fixed data background, a list of major contributory lab data, a list of changes on treatment and then there should be a space on which you can type or dictate, a discharge letter. I find it incredible that we never got to that stage in our professional lifetimes and neither have the DoH achieved it after spending more than £12 billion on IT consultants. I ask whether these new factors have actually been the subject of any work by anybody? Has there been any progress in this particular area?

Will: Can I shelve that just for the moment? Mike, you wanted to say something about the structure of the program and I think you've now heard a rehearsal of the sort of things that people anticipated, did and wanted to do. Is that of any help in focusing your comments or are you still slightly at sea about what is it the clinicians wanted?

Gordon: Well, I'm not sure about the individual items. What I do know, as I said to you, I want to explain what on earth an account of commercial enterprise is doing in the middle of this meeting. It's not to plug the commercial enterprise. The commercial enterprise came out, fell out really, because it was clear that support for the work at Charing Cross hinged entirely on Hugh de Wardener, who wasn't that far off from retirement and the politics in that department were pretty clear as to what it would do (or, rather, not do) to support the work afterwards. It also came out, in what was really a slightly fanciful moment, when I said to the Professor: 'Well, you know I think this thing is good enough, it could almost sustain a company.' Normally when I say such things, a day or two later well, I've forgotten them. But the Professor said: 'What should we call it?' which kind of gave it momentum and I asked him to check out the idea with the medical school. And in due course we got on with it.

So for a while, the project had one foot in the department. Then one day in 1979 Martin Knapp turned up in the department because he'd heard we were doing this work and as I recall, Martin, you said to me: 'Well, we're thinking of developing our own system but you guys are clearly so many light years ahead that there's no point.' And so it began to gain momentum. I had no idea what I was getting into. I think I had some vague idea of a kind of corner shop, I suppose, because my parents were shopkeepers, and that's pretty much how the finances played out as well. But from the time we started to address Martin's problems, in 1980, they were different from what had been done at Charing Cross. They weren't different in any deep, generic sense, but they were different in the detail. The first thing, as I recall, was for hypertension markers to be displayed above various other variables. Then I think, a year or so later, came Es's system, and that was different again. And then came Liverpool, that was different yet again. Now there was only one programmer, who by this time was tearing his hair out. [Laughter].

As it happened, I had formulated some structure for the data and I think Conrad probably did pick this up. Then what emerged was that it was possible to write the thing in such a way that the software that made it work was separate from the definition of what data it was handling and how it was to display it and so on. I think probably that idea is buried somewhere inside, for example, Windows systems, because you can set them up to a certain extent to be the way that you want them to be.

Venn: But you can't change them fundamentally.

Gordon: Well no, but you couldn't change what became Proton fundamentally, could you? *You* could, but not end-users. As to the actual clockwork inside, I think personally that there was a change when we finally had to give it an enquiry system to analyse the data and that was allowed to change some things. Conrad thinks we released too many upgrades to the central system. I don't know. But, because we had a very limited sales capability, and because you could make it look like all kinds of things, while still keeping the bit in the middle unchanged, that wouldn't be tampered with except by the developers, in a way a mistake was that when Andy Webb joined us he was probably more interested in sales than I was, and he found that he could demonstrate to clients how easily it could be changed. I don't think it really got out of hand, but we had clients making changes to suit themselves. That was one reason why people really liked it, I'm pretty sure, because they could feel ownership of it. I imagine that was not sustainable for the long term and certainly it doesn't seem to be happening in the States from what you've said.

We kept costs to the NHS to what we believed was affordable for them. Unfortunately, if understandably, sales were difficult. In one case, a sale agreed in principle by the client took the next five years to materialise. Beginning in 1983, the product attracted interest from some US centres, who bought it, including the Mayo Clinic, but we didn't increase the price. The first sale that really got us somewhere was in 1992, to National Medical Care (NMC) in the US, who were later bought by Fresenius. Fortunately, despite a huge discount on the software price of each system, the sale rescued me from near-terminal personal debt incurred in keeping the company going. NMC owned many centres and continued to get more of them by buying up other dialysis centres. Every centre had the same core software, which meant that we could maintain the core while they looked after the user requirements. So they did impose uniformity, whereas the UK in traditional style, everybody was doing his own thing. But this made it possible for the central core to be progressively developed by us, but in a way that let people add their own aspect, their own requirements to it. Eventually there were some 2,000 centres using our software, linked back to NMC's mainframe, a connection which Conrad helped to implement. I don't think we would have got anywhere if it hadn't been able to do that because there really wasn't any agreement on requirements in the speciality elsewhere. I went to one meeting at the Imperial Cancer Research Fund to define a standard dataset, and people came from all over the country, and they left having only, I promise you, only agreed that they should store the surname. And eventually the first name, because, let me get this right, there was a discussion about whether you could infer the gender from the first name. I think we got to the end of that. There was a further discussion – this was early days – about whether you could infer the age from the birthday or vice versa, in which case you needed only to record the age. At the end of the day, everybody went home and there really wasn't a standard dataset and I think now, perhaps that was in the English temperament, a dislike of regimentation.

Before NMC arrived, we were fast running out of money, and we'd also, so to say, run out of renal units. A number of diabetic units, I think 12 or 15, after a lot of persuasion, took it up, and it worked fine for them because of its adaptability. And, in the meantime, various other people had caught on and, as I recall, there were 19 different medical specialties using it, 3, 4, or 5 large maternity centres, with various other people using it more or less experimentally. It was the fact that it was configurable in this way that at least let it get a foothold. I don't suppose that can be the long term. Yes, there was this issue of ownership. There was evolution.

Will: I'll just come in on that. There is an issue about whether this British way was a necessary or essential part of the growth of the system. In other words, was it crucial that people could see themselves in the system as they led their units into IT functionality? And was that a real driver, not only that they could address their preoccupations, whether it be in dialysis or hypertension or transplantation, but actually they could also somehow characterise it as themselves. Coming back to Peter, how can you engage people who didn't actually start up a system?

Gordon: I'm absolutely certain that it would not have gone anywhere if it could not, at that stage of the game, meet the individual requirements. Martin said this, everybody said this.

Sells: Absolutely right. I agree.

Rowe: I really don't think the requirement, or perhaps desire, to engineer systems to meet local needs has changed at all. If you look at other clinical services, every unit does something just a little bit different with the same basic data set. We've been working through the Clinical Reference Group for Renal Transplantation to try to write a single generic service data specification across the UK, but its proved almost impossible. Actually, that's part of the richness of medicine and that's why a system that's useable has to meet that requirement, which is what Proton did, through accident or design

Gordon: Well, it was a kind of intuitive development –there's no question about it – which, as I've said to you, I think I now know what is a common structure for clinical systems, but I think Conrad intuitively built that into the nature of the system. I think it embodies a description of the way – there must be some exceptions, got to be – but I believe it's the way that almost all medical units or centres work.

Rowe: I think it's also why most major computer systems that have tried to provide comprehensive EPRs have failed, because they try to make people fit one model.

Gordon: Yes, eventually I got to thinking that if the thing was richly enough endowed with features, people would be willing to change their working practices to make use of it, and I think that has possibly succeeded in some places.

Will: That's what I was trying to put a finger on, because Keith started, or at least part of his initial discussion, was why a lot of colleagues don't immediately see this as a highly entertaining and desirable thing to do. You said you have to actually identify the user with the system, and this is what we were tip-toeing around when we were talking about engagement. But there is a necessary balance of uniformity and software support, which obviously hasn't gone away. What we're saying is, if some clinicians don't see that they can put their face on the processes in their system, they will take their bat home; they won't actually wish to be involved. So this is not only a desirable thing, for many people it's absolutely essential. It raises a conundrum of the balance of differentiation versus uniformity, doesn't it?

Gordon: One other thing was this input which was derived from MIT. I have the feeling that there's a difference between what I'd call standard computing and what I call imaginative computing, which may only mean actually where the frontier is – I don't know. But the place for it is MIT. There's a book called *Hackers*[61] – that doesn't mean the sort that rob banks. In those days it meant guys who love computers. The author is extremely entertaining and describes a group of people who really adopted minicomputers as a kind of religion, seriously – they lived for it. And what we had in a way was a very fortunate thing: a speciality that had this wide range of variables being measured, and also measured over time, with somebody extremely good at programming, who was prepared to face up to the not-for-squeamish-people aspect of medicine, and the fact that we got these ideas together so that input was very easy.

Something I don't understand is why nobody seems yet to have made much use of speech input, which is clearly getting better and better.

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[61] Levy (2001).

Will: Dr Wachter has a particularly optimistic view on that.[62] Martin?

Knapp: I wanted to illustrate the point made about pleasing the user if you want them to use a system. In 1983, after I left nephrology at Nottingham, I transferred myself to Obstetrics as an 'Information Unit'. This was supported by Malcolm Symonds, Professor at Queen's Medical Centre and also at the older Nottingham City Hospital. The City Hospital had planned to develop computing using a system that was developed directed by the Regional Health Authority, with the emphasis on collecting management data. At Queen's we directed the computing at the process of having a baby, which really is just the same as having a transplant in many ways, making the CCL system very highly suited to it. The midwives are, I think, a bit different from renal nurses but certainly they are very strong-minded people and very important. We had realised from talking to colleagues around the clinic that it was a good idea to please the people who were important. So we set out to please the midwives. Their main gripe in life was the amount of paperwork they had to do. With the help of Conrad at CCL we focused on the activity at the end of delivery, when they had to send all the paperwork off to the various departments. It had taken two hours after a baby was born before that job was completed. By focusing on the post-delivery process, we got great enthusiasm and the thing went very well. At the other end of town, the focus was on producing information for the Regional Authority, who had funded that particular unit, with funds provided by the Korner initiative. There was very little gain for the midwives in that system and when Christmas and New Year came around and all the computer development team went home, the system was turned off. When they came back, at the City Hospital the midwives just refused to use the system – they'd just had enough of the extra work putting in management data and with little visible return in reducing their administrative load; at Queen's the Obstetric department was able to produce management data with much less work using the CCL system, which had been fed data in real time by the midwives and was later available as stored data for management.

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[62] See page 82.

Will: You're hinting that there's more to it than the logic of sub-speciality, per professional, responsibility for data entry. In a way renal IT was an educational experiment analogous to the project of the Indian educationalist who put a computer in a wall in New Delhi to make it available to street children. Within a short period, and I don't want to bowdlerise the whole story, but basically the children worked out, as a group, what to do with the computer and ended up running it. The computer was provided and then everybody did what they could with it. There was a phase of exploration and proliferation and not in that sense, integration, function or understanding.[63] It was just a phase and explosion of application. Conrad?

Venn: Just on the issue of people needing to tailor systems to their own use. I think, in the very early days especially, the flexibility was absolutely essential because what effectively we were supplying was a building kit, a Meccano kit of kinds, perhaps with an example, a sample application or part of an application, but we didn't have a full-blown application that would cover all the different aspects of renal medicine. It covered a lot of them, all the lab data and so on, but it wasn't by any means a complete application, so people actually had to add to it to build a fully working system.

Will: Part of a unit-wide eco system.

Sells: I agree very strongly with the proposition that some degree of flexibility gives a sense of identity, a sort of relationship with the system, which is absolutely vital. Early on, a senior member of staff in Liverpool had difficulty because he was suspicious of the computer and did not have a relationship with it and it was important that he should actually start to use it. And it wasn't until he saw a junior nurse using it, he looked over her shoulder and said: 'What are you doing?', she showed him and he was completely convinced.

Will: You're saying the role modelling can be really very important. Andy?

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[63] Mitra (2012).

Stein: I was just going to say, I suppose I consider myself about a 'third generation' nephrologist. I went into it in the late 1980s early 1990s, when Proton was up and working in Leicester. And I don't really ask the question about why Proton had come in. I just thought 'why would it not have come in?', because it's a small specialty, critically below the Dunbar number, i.e. less than 120 units is at the lower end of the Dunbar number (i.e. 150). It's a new specialty that came along and as you know its origins were probably in the early 1950s. It attracts mathematically-minded people that aren't particularly interested in private practice and power and all the rest of it. So maybe it started partly as we had the coincidence of two very clever people around at the same time, who produced something that Mr Sells said there was a clinical need for; and we found that it worked and was adaptable because you had the vision to make it adaptable. So why would this not have happened? And then throw in some luck, ie Martin had a lot of money at the time, or some money, to be able to pay them. So there were a few things that happened at the right time in a speciality that was asking for it; and then out of that you can see why there's no national database for diabetes or breast cancer or anything else.

Will: Very possibly.

Gordon: Two very quick things: one was, before we got going with the PDP11 – I was doing some stuff on the systems, the PDP11s, at Imperial College and we had all sorts of very encouraging-sounding messages from the Department of Health. They had grants that would support future things, and as a result an awful lot of work on our part went on in the small hours, to provide a demonstration, but finally the DHSS told us: 'Sorry, chaps, the committee structure has been reorganised. The committee you were dealing with doesn't exist anymore. We can't be sanguine about your proposals.' And then later, after we were on the Clinical Computing side that emerged, the Department of Trade and Industry did a survey and there were a lot of American centres interested. Then I heard that the DTI had set aside some money for us, but then I heard that the Department of Health had said: 'The Department of Trade and Industry cannot give money to any medical projects.' So that was that. So we were kind of on our own, and we weren't getting an awful lot of help, nor did existing IT centres.

Will: It nearly happened in trade but not in health!

Gordon: Right.

Will: I want to finish off by talking about the CCL Users Group.

We can say that early on the groups, both the BRCG and the User Group, contained clinicians who were actively working on the system and also these computer managers, clerical people and so on. But, as we moved into the 1990s it became clear that the User Group was best formulated by the non-clinical staff because they were the ones who were wrestling with the applications, the maintenance, and all the things that actually needed some policy-related coherence to develop. Their meetings came and they went, but they were better attended latterly by regional-based computer data managers, and the clinicians actually fell out of it. Presumably medical time was highly limited, and as Peter said, one went to meetings that one thought might be beneficial.[64] The CCL User Group developed, then, into a forum for the IT managers.

It also had an overseas component, which was a completely different issue, of course. The thing I remember causing most concern comes back to the Quark enquiry language, where some of the enquiries about demographics and specific interests became really quite complicated and were enabled perfectly well by the software.

The problem was, could they be distributed, could they be disseminated, could they be supported? So there was discussion about the enquiry system, about whether or not there should be a group that would supervise it nationally, perhaps with a Quark library. That would have been separate from the BRCG and yet it

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[64] See page 84.

would have been one of the main foci of the national renal IT development. Barbara, that covers most of those issues, I think, but you were the person who worked to keep this group going in the 1990s, recruiting people to come and that kind of thing.

Temple: Yes. It really started in a very, very small way, when the first systems were bought, because when Hazel at Charing Cross demonstrated it, as we were leaving she said: 'If you do get this system, any problems, give me a call and I'll help you out.' And that's really what started it because as more people bought systems the computer managers, if you care to call them that, would ring me and say: 'Look, I want to do this but I'm not quite sure how to do it. Have you done it, and if so how did you do it?' And that's how it really started, word got around. Then I thought: 'Why don't we just meet, rather than talk to each other on telephones, why don't we meet as a group?' And that's how it started, I think somebody suggested: 'Well, why don't we do it in two parts? In the morning we'll have our meeting and then perhaps some of the consultants might be interested to come along in the afternoon to talk to us and tell us what they're looking for and that sort of thing.'

It just took off from there. Then CCL would come along and then eventually CDS (Clinical Data Systems (Ltd)) got involved, because they used to come, presumably to try to sell us some more hardware. They got to be quite big meetings, and we'd meet in different hospitals. But then, of course, it seemed to die off and, as you said, when Quarks came in, it seemed to regenerate itself again. But it actually started in a very small way.

Will: At any given moment over the three decades, there has, generally speaking, been a national forum for people, not always the same people, who are interested in renal IT. So there was the BRCG, there was the CCL User group, the UK Renal Registry committee was for colleagues who were interested in contributing, with an annual national meeting, and after 1995, John Feehally started the RIXG group (Renal Information Exchange Group) of the Renal Association. It has always taken slightly different forms but people with enthusiasm and interest from the nephrological community have always found some use in getting together, not always around the same concerns, but thinking along IT lines.

Gordon: A resource that I failed to understand just how valuable it could have been to us, unfortunately. I want to say one, I promise, last thing and I forgot to add this to the bit about the Department of Health. There was one small come-uppance which I witnessed, in that there was a meeting, I think it was at the Royal Society, if I remember rightly, precisely about the application of computers to medicine. A rather self-important person came from the Department of Health, and the various speakers explained what they were doing. At the end this chap stood up and it was pretty clear he was standing up to tell them why they weren't doing things right and why the Department of Health knew better. What brought this story to mind was the nice panelled room here, because the lecture theatre there had wood panelling all the way around, modern wood panelling, grooved, high quality panels; small grooves.[65] He held the microphone and made these initial remarks. Seemingly pleased at having established his superior understanding of what needed to be done, he leaned back against the panelling, and there was a concealed door. [Laughter] He vanished! [Laughter] All that was left was the microphone wire going into the panelling, which had closed again. The biggest mistake that he made was to come out and attempt to act as if nothing at all had happened. [Laughter] Unlike a Swedish expert who I once saw at a meeting who got onto the dais and walked across, fell flat on his face, then got up and did this (he smiled, unfazed, and shook his joined hands above his head, in a cheerful boxer-style salute). And everybody applauded loudly. There you go.

Will: So we go from cottage industry to knock about.

Gordon: Yes, well, there was some of that.

Will: Well, the last two elements we thought were needed to round off the meeting. What I wanted to do is briefly sketch what I thought ended up as the more

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[65] Part of the Witness Seminar was held in the wood-panelled Censor's Room of the Royal College of Physicians.

difficult elements of the BRCG and then lead on to how things changed after 1988. Then perhaps discuss what exists today and whether or not our extensively shared experience has anything to say about modern renal IT.

I would like to start with some of the things that got in the way of the Renal Computing Group. Some of them were entirely incidental, of which one of the more interesting was the failure to follow up the novel computing section of the annual EDTA-ERA meeting in 1986. Only the abstracts achieved publication, a series with a strong UK contribution that was never promoted again in EDTA-ERA.[66]

There were also a series of cultural and policy issues, which potentially got in the way. Every time myself or other people tried to make contact with what we might think of as the Establishment in the Department of Health or other agencies, we were just simply either ignored or certainly never made the contact that we might have made. I have letters on file sent to the Department of Health at a high level requesting involvement in a series of IT-related projects, requesting seats at a table when IT was being discussed in an appropriate context, for example. Never any response. The Department of Health, I believe, did have policies that were actually not supportive of departmental systems and they didn't seem to discriminate between renal and other systems at all. The Regional Health Authorities, after Griffiths in 1982–83, when the NHS became more bureaucratic, obviously didn't have anything to offer in this clinical IT context.

At the hospital level, as we hinted, the IT departments were not particularly helpful. The renal systems were seen as cuckoos in the nest and were not facilitated and, since they were not producing data that the hospitals could use for their own purposes in terms of finance, they ended up unsupported.

Approaches were made to the English organiser of the ISN (International Society of Nephrology) meeting in London in 1985, because by then EDTA-ERA, at least, had cottoned on to the fact that there was clinical renal computing. ISN simply

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[66] Computer Abstracts XXIII EDTA-ERA Congress, Budapest (1986).

didn't respond to a carefully constructed letter proposing the demonstration at least of clinical IT. That too was an opportunity that UK computing simply missed out on. That would have been, you would have thought, a feather in the UK cap, but it just didn't happen.

And then there were the other things that we have been talking about. The EDTA Registry digitised returns got to a point of two dozen units, but the EDTA Registry itself ran into problems and gradually declined in effectiveness. Despite a lot of effort, there were missing data, unreconcilable patient movements and so on. It got steadily worse and the EDTA returns in the end rather collapsed.

There was, as I was hinting earlier, some clinical scepticism about some of the computational applications, including urea kinetic modelling, and people settled for the much simpler urea reduction ratio, which was easily collected and displayed.

There were restricted opportunities for publishing and we mentioned this extraordinary *Kidney International* volume in 1983.[67] In 1998, notice the year, Keith and Mike Gordon got their paper into a mainstream journal.[68] In between, as the bibliography shows, renal IT publication was really quite piecemeal, demonstrations, conferences, and so on, and there was no major way in which the clinical activity, particularly, could be, or was, projected. There were some notices in the *British Journal of Healthcare Computing* but that's all.[69] Essentially the journals insisted on evidence of results from the methodology. They wanted studies, they wanted evidence of change of behaviour or whatever. Now, some of that came later but would have to be talked about in the context of the Renal Registry, not before 1994.

All of these things added up to a failure to influence events. There was no formal connection to the Renal Association, there was no association to any of the formal

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[67] See pages 50–52.

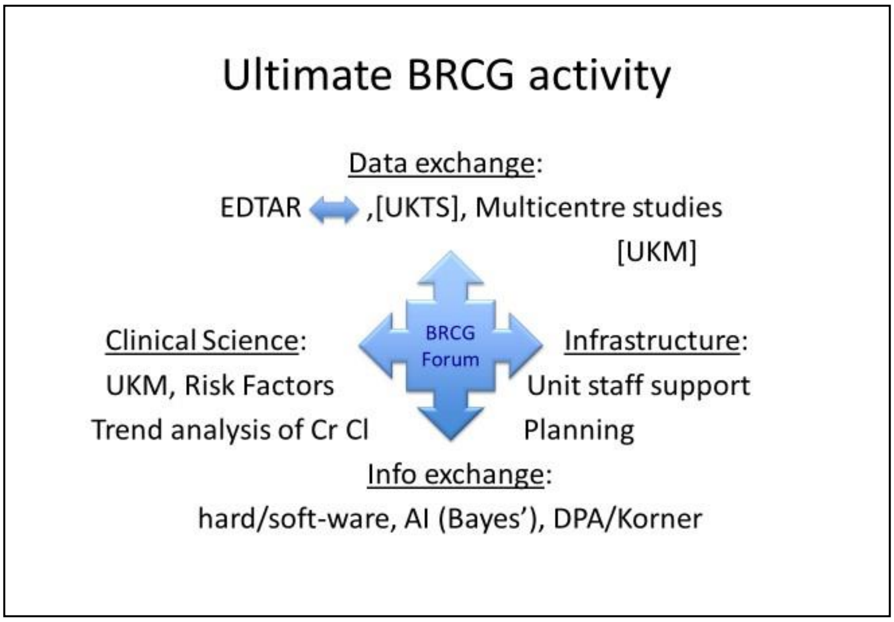
[68] Simpson and Gordon (1998).

[69] For example, Will (1984); Selwood and Will (1985).

bodies. The hospitals at local level refused to consider regrading and the proper placement, if you like, of the renal computer support staff. Of course, going on throughout were the CCL User initiatives, which were in parallel to the BRCG but couldn't actually be adopted by a non-commercial group. That is the dystopic side of the BRCG activity. Under those circumstances, it might not be surprising that the attendances tended to drop and the attendance at the last meeting in Glasgow was rather lower than it might otherwise have been. That's not to say there wasn't still a lot of enthusiasm in some places, but it wasn't generalised.

Are there any points of that that people would like to pick up before I go on perhaps to the post-1988 scenarios? Have I covered the background?

Goggin: There were minor journals that sometimes took some of these things and one of them was called *Medical Informatics*. The person running that was John Anderson who was a medical professor at King's College. He would accept some things that were based on a description of the technology and just the results that it could produce rather than some large studies showing how it affected clinical practice.[70]



Ultimate BRCG activity

Data exchange:
EDTAR ⟺ ,[UKTS], Multicentre studies
[UKM]

Clinical Science:
UKM, Risk Factors
Trend analysis of Cr Cl

BRCG Forum

Infrastructure:
Unit staff support
Planning

Info exchange:
hard/soft-ware, AI (Bayes'), DPA/Korner

Figure 9: BRCG Activity

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[70] For example, Goggin (1984); Goggin and Hoskins (1985).

Will: Yes. One of the interesting features about the renal IT scene is how little attempt there was to make contact with the British Computer Society, for example, or other groups – the intensive care group and the obstetrics group that were also running clinical liaison groups. In the BRCG, in retrospect, everyone was very busy with their own issues, and didn't actually look outside. This may have been a cultural narrowness, and it was why I asked earlier about Conrad's experience of others judging his progress, for example, because it didn't necessarily occur to people to try to make those links. The British Computer Society did produce some recollections and reflections relating to the times, but they only used the limited published material in the clinical specialities and therefore do not convey the range of activities and the energy that was going into the renal scene at the time.[71] This meeting puts some flesh on those bones.

Bone: Wouldn't it be a reasonable or possible explanation that once it was up and running, it became part of the wallpaper and as far as the Department of Health was concerned, it would be just a question of 'it's happening so why bother? What else do you want to do?' Everything else would have been absorbed into the various budgets. Unless the sky fell down there wasn't anything else to do?

Will: It's probably fair to say that there were not a lot of initiatives with which we worked in that period. Later on, of course, there was the Clinical Terms Project but people turned to the established agencies to get representatives, so they turned to the Renal Association or to the College of Physicians, who actually had no connection with this informal group. If those organisations don't actually adopt special interest groups to some extent then clearly the interest is not going to thrive. It's interesting that in Stewart Cameron's history of the renal association, individuals interested in haemodialysis in 1966–68 were exchanging information and thinking to set up a group to pursue an interest in haemodialysis but the Renal Association, in its wisdom, incorporated them pretty quickly.[72] So this kind of

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[71] For example, Barnett (2008).

[72] Cameron (2000), part A, pp22-23.

predicament has happened before in Nephrology, with a different outcome. That special interest dialysis group disbanded after only two years in 1970.

Rowe: So in terms of engagement with the establishment I think also the climate has changed quite significantly in the last ten years. There's now much more interest in translational research than there ever was before, when research was driven by basic science predominantly. It's my feeling, in the early stages and particularly in renal research, the RA were much more interested in the physiology of the kidney and detailed mechanisms rather than things that would change the way we delivered the clinical services. The DoH have been really slow to wake up to that reality too. You can now get funds more easily, grants for translational research are readily available; if you can think of a way to improve healthcare you can get resourced because the DoH is interested in making healthcare better and more efficient. But that's come very late in the day and I think we were probably a bit before our time.

Will: Well, I was going to say that the phrase 'health services research' didn't exist.

Rowe: That's a service delivery aspect.

Will: Well, it all is. In Scotland there was actually a little more appreciation of that, for all sorts of different reasons. I have spoken to Brian Junor, corresponded with him, it's unfortunate he can't be here, he would liked to have come. He mentioned that one Friday morning he rang the nephrologists in Scotland and said: 'Shall we have a registry?' I'm paraphrasing inevitably, but the point was that such ideas were moot, and in a smaller group where he could make contact, then that could be set up really quite quickly. I think by 1991 things really got going and obviously the issues were just ready to crystallise along those sorts of lines. As you say, perhaps this was all just a little bit early and we might also fold in the observation that Terry made previously, that organisations can have a life and then dissolve because they've done the job. I don't know how true that is in this context but there's a sense in which the BRCG was overtaken by events. Are there any other thoughts about this?

Sells: What happened in 1986/87, who cocked it up? Or was it just exhaustion of a disabled system: 'Oops, you seem to have lost a year's data.' Tell me why that happened?

Will: The gap in EDTA-ERA Proceedings you mean? I don't know. They used to publish the Proceedings of the annual EDTA Congress themselves and in 1986 they transferred to a journal publication (*Nephrology, Dialysis and Transplantation* (*NDT*)). In that transition, everything but the abstracts got lost. It was a Freudian slip in a way, you know, the sense that nobody was interested or keen on it, so it got lost. Whether they felt that the computing section in 1986 had been a failure in some way, I don't really know. It seemed to me it did actually represent quite a lot of particularly UK activity that was going on at the time. So personally, it seemed to be a definite loss.[73]

Well, if I can move on, we need to think about the end of the group in 1988 and focus on the 1990s until 1994. By then a number of other things started to influence the cultural scene, which might have further increased the focus on clinical IT. In particular, there was increasing interest in evidence-based medicine. This was expressed quite formally in the instruction from established agencies to undertake audit of various kinds. In 1990, north of the border, clinicians working up proposals for a Scottish Renal Registry found that the funding body preferred that 'and Audit Group' be added to the title of the new initiative. As well as producing an unwieldy acronym it reflected only one of the clinicians' enthusiasms and was subsequently dropped. However, the episode is evidence of the development of new uses for clinical information.

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[73] Dr Es Will wrote: 'I was over-interpreting any injury here, although there was no subsequent attempt to repeat coverage of clinical computing at any ERA-EDTA Congress. The transition to journal (*NDT*) publication caused delay also in core EDTA Reports and only in 1988 was the demographic material from 1985-86 available in the journal. Supplements to *NDT* are indexed from 1990. The EDTA-ERA Congress details are available on-line only up to 1985 (number 22), at http://web.era-edta.org/proceedings (accessed 30 January 2018).' Note on draft transcript, 31 January 2018.

Simpson: Yes, the clinicians thought firstly of the Scottish Renal Registry and then the funding body said we had to add the words 'and Audit Group'. We got rid of that pretty quickly.[74]

Will: It's evident that at the beginning of the 1990s there was a shift. There was also an interest in risk factors after a seminal paper connecting relative risk of mortality with serum albumin, a linear relationship.[75] Colleagues became more and more interested in what the lab data might be trying to tell us, and there was a lot more interest in risk factor calculation.

The Department of Health too became interested in what were para-clinical issues, in the Clinical Terms Project and in Case Mix and the Diagnosis-related Group concept acquired from the United States. These were some of the movements that occurred in the early 1990s and I think it led to greater recognition in the establishment, if you like, of the place of the IT. There was a much stronger sense of buy-in from the Renal Association, leading ultimately to the UK Renal Registry. The work on that obviously started in the early 1990s and developed as the case was made and crystallised.

Sells: I find it extremely interesting that following the 1991 paper about the dangerous conditions which arise from the low serum albumin, there was a hurricane of interest, probably in a defensive mood, particularly in America, particularly in the intensive care environment, where albumin all of a sudden became the pivotal point around which everybody had to concentrate. 'What's the serum albumin?' would be the first question. And then the recent clinical trials, about three or four, one of which I read in the *New England Journal* recently, was that patients who received very energetic albumin therapy did very significantly less well than the people who do not.[76] Maybe that's just a little bit of a warning?

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[74] Simpson (1993).

[75] Lowrie and Lew (1990).

[76] See: Stockwell, Scott, Day, Riley and Soni (1992); Cochrane Injuries Group Albumin Reviewers (1998); Pulimood and Park (2000).

The translational, if you like, outcome was exactly the opposite of what the original paper was saying. Is that right?

Simpson: Was it not the other way around? I think the paper showed that if you naturally had a good albumin you were doing alright whatever anyone else said. It's a marker, so you can't just give albumin, in the same way you can't just give blood.

Sells: Wasn't it the enthusiasm for intravenous albumin treatment in intensive care units that sprang from that?

Simpson: Yes, it was phenomenal. Yes, enthusiasm but they got the logic wrong.

Sells: Yes, but I hold that out as an example of what one would like not to happen when the seamlessness of transition from good data to very good clinical results as a result never happened.

Will: But those were acute studies. There have been studies trying to increase serum albumin –

Sells: Be careful what you do; you might not get the result that you want.

Will: Perhaps. There have been studies trying to change the serum albumin on a sub-acute, on a chronic basis, in dialysis patients and they failed. It is a sign, not a consequence, It's a marker. Francis, how was this taken in the States?

Dumler: There are some interesting things. The original paper was by Lowrie and Lew, which is the one that showed that low serum albumin was a predictor.[77] When you read the methods you find out that the serum albumin that was used was the first albumin at the time of the first dialysis procedure. And that single

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[77] Lowrie and Lew (1990).

value on day one of dialysis predicted that you were going to die five years later, which intuitively is very complicated.

Will: It wasn't serial data, is what you're saying?

Dumler: Right. Later on, they published a paper with serum albumin as a time-dependent variable and the results seemed to be about the same, though it was not the same patient population.[78] The other issue is that low serum albumin concentration, as we understand now, means one of two things. It means significant inflammatory state, or it means primary volume overload. I actually published some studies showing on CAPD patients all the serum albumins were significantly lower.[79] We did body composition and they had increased total body water, if you ultra filter the PD patients you will get their albumins to a relatively normal level. Studies of trying to improve serum albumin without using aggressive intravenous therapy basically boil down to removing catheters, treating infections, providing some nutritional support and really minimising inflammatory processes. And those albumins rose. But in the long run there wasn't much of an outcome, but I don't think there was a long enough period of study to try to determine if mortality a few years down the road was going to change.

Will: One of the problems of controversial publications, I think, is that they get a head of steam for one reason or another and then provoke belief in the most plausible consequence or implication. We've seen it with managing renal anaemia as well, where incomplete description allows a penetrating misinterpretation to take centre stage, whatever the logic. That phenomenon begs a name!

Dumler: I think that the more recent data, the better data, is from Kalantar-Zadeh studies in Southern California.[80] For example, he used the DaVita database, so he got 50–60,000 patients followed over a number of years and the low serum albumin was a predictor, but if you added a high CRP (C-reactive protein) the value

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[78] Culp, Flanigan, Lowrie, Lew and Zimmerman (1996).

[79] Dumler (2003).

[80] Kalantar-Zadeh, Kopple, Humphreys and Block (2004); Kalantar-Zadeh, Kilpatrick, Kuwae, McAllister *et al* (2005).

of prediction fades. And then if you added a high value weight then they got better, and if you saw that their cholesterol was low then that was bad, but a high cholesterol was good. So, at the end of the day, you have markers that are reflecting certain processes, which are not really clearly understood. Nevertheless, you get penalised if the serum albumin is below a certain value.

Feest: It's the classic problem that registries are always dealing with. In fact, it's an association being interpreted as cause and effect. What we know is that low serum albumin is a marker of all sorts of illnesses that shorten your life. It's the same logic that most people die in bed and so you should never go to bed. [Laughter]

Will: Well, in the event, we might think it remarkable that UK renal clinical computing is still available and lively. We do have some kind of snapshot of that, not perhaps current, but as part of the RIXG group that I mentioned earlier from the Renal Association. Keith Simpson, and colleagues did a review of the facilities that were available within the renal computing environment in the UK in 2006.[81] Keith, would you comment on that survey and what it said about the heterogeneity of units as a late consequence of what we've been talking about?

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[81] https://renal.org/wp-content/uploads/2017/06/Renal_IT_functionality_-_2006_survey.pdf (accessed 23 January 2018).

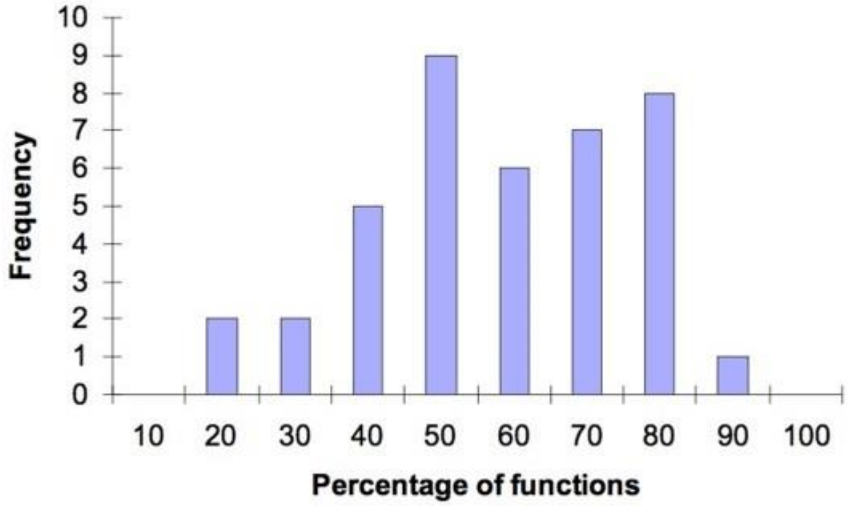

Figure 10: Proportion of functions reported by renal units as present in their Clinical IT. Reproduced from Keith Simpson, Functionality of Renal computer systems. Report for the Renal Information Exchange Group, 27th March 2006 https://renal.org/wp-content/uploads/2017/06/Renal_IT_functionality_-_2006_survey.pdf (accessed 23 January 2018).

Simpson: Well, I think it just showed there was a wide range of tasks that had been computerised and that different units had gone for different things. Some of the things were certainly very clever and sophisticated. What I found surprising at that late date was that take up of IT tools wasn't all much higher and wondered why weren't physicians ranting to get it?

Will: So, we might say that the clinical correspondence was available in half, and what you'd have to say was: 'why not all?'

Simpson: I agree. It is very odd. Clinical correspondence is a core activity. Hospitals get paid for doing it and we get nagged by management that we have to write to GPs on time, but most units did not have computer systems that would enable them to do it.

Will: What agency is responsible for the clinical computing in renal centres, would be one question? If we say: 'Why is this still like this?' What agency is responsible?

Feest: Well, it isn't still like that, that was 2006.

Will: Has it changed since 2006?

Feest: They've all got systems.

Will: Well, they've all got systems but functioning with a different spectrum of input and how much they cover. What I was just trying to bring out is that there may be a central direction of what data should be acquired and reported, but there isn't actually any central organisational element for this function within the NHS. Am I right?

Stein: Yes, I think you're right. The Renal Registry obviously has its functions and that overlaps with other bits of the renal registry now; but as far as I know, the Renal Registry's job is not to impose systems on units or to check they're doing it, is it? Do you see that as its role? To be an IT policeman?

Dr Fergus Caskey: We have a data set, which will hopefully soon become the National Renal Data Set to replace the previous National Renal Data Set, but we've had a big discussion about this recently. We do not see it as our role to tell renal units what to put in their IT systems.

Will: Fergus, can I ask you, how then the dataset could be promulgated? We know that there are data requests that are neither fully completed nor accurate, I think the words 'stubbornly resistant' have been used. Can you see how that will ever be improved unless we get to a point of spreading expertise in the IT side, or are we condemned to be victim of this history? Because a lot of this seems to be based on the history of what came into a particular unit at a particular time.

Caskey: Broadly speaking there are two ways: there's the carrot and there's the stick, and from a carrot point of view it's about trying to make the registry more useful to clinicians. Keith can probably talk about this more than I, being very involved in UK Renal Data Collaboration plans. Trying to get real-time data into the registry, the ability to transfer data about a patient to a holiday dialysis unit, would be one example. But also real-time audit rather than waiting 18 months or so for the report to come out, being able to interrogate the registry database for regional or local or against national data. So there's lot of clarity-type things that we're really hoping the UK Renal Data Collaboration will allow us to do, and will then make people want to invest in the renal IT to be able to have that functionality. The more difficult thing is the stick side of it. The clinical reference group, which is now a single group for dialysis and transplant, is working with the commissioners to make the service specification more explicit about what is meant by supplying data to the registry so everybody knows. I'm sure it is written into the service specification for dialysis that people submit data to the registry, but compliance with that is not defined and so they are working to make more explicit as to what qualifies as submitting data.

The other thing I mentioned to one or two of you is that the commissioners have now approached us, with their NHS England legal basis for requesting data, to provide them with monthly data on certain measures that they can then provide to the people who commission services from renal units to look at – particularly acute dialysis or, for example, transplantation activity or dialysis treatment rates for expansion, or whatever. I think that will help focus minds. Somehow within that commissioning work we hope to make it financially sensible for the hospital to invest in its renal IT infrastructure and data submission to UKRR.

Will: Thank you for that. Obviously, that exposes how the service organisation has changed, so that the incentives and the disincentives have been reorganised.

Feest: Can I just come back one step on what you said? You were asking what body is responsible for ensuring these things are put in, but we beg the question of who decides what things should be put in? We're talking as if we know what should be on these systems. Who has ever actually sat round and said: 'This is what should be on the ideal renal system?' The danger of doing that is that in three years' time we'll want something different. So I think we've begged a question there: if we go back to your analysis there were lots of things that were on some units and not on others, but who's deciding what should be on?

Will: Well, in a way that's the question I was positing. There isn't actually any central agency that raised all of those issues, but it's been a changing scene anyway because of different demands.

What I was just wanting to bring out to close the 1988–1995 issues, was to compare where we started to where we were in 1995. Jeremy Wyatt at that time was medical informatics manager at the ICRF (Imperial Cancer Research Fund) and listed, in the *BMJ*: 'There are many (IT) pressures including the desire of clinicians practising in evidence-based medicine, to access the exploding clinical literature.' That was not relevant in 1983 in that form at all. 'Increasing patient participation in decision-making and self-management', I can't really see where that was involved at the beginning. 'More extensive teams of professionals who manage patients using shared records.' Well, that was an element, but it was largely internal to the specialist units. 'Concerned over the confidentiality of patient data.' A hole has recently been rather blown in that by the Royal Free Hospital, but nevertheless we were put through the hoops of the Data Protection Act in the mid-1980s and the computing group actually offered formal advice about that. And then lastly, 'the complexity of the contracting process enforced by the purchaser–provider split'.[82] So few of the concerns he was promoting as reasons for wanting to develop the IT in 1995 were the prompts we started with. When you look at the British Computer Society advice about how you set up a modern IT installation, the start of the clinical renal programmes fulfilled none of their criteria. There was no detailed plan, there was no designated prospective funding, there was no infrastructure. So it started like topsy, like a cottage industry; it didn't actually fulfil any of the criteria that people have come to, or even at that time, would have argued were essential. It's interesting even in the mid-1990s to see how the clinical and the bureaucratic environment had changed from the end of the 1970s.

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[82] Wyatt (1995).

Sells: But you're not surprised about that? I mean you can't be, Es. If we all go back 30 years, what would you see? You would see 20 deeply enthusiastic, excited people in a field which was expanding extremely rapidly, where the results were beginning to look good, where the dynamic process of pre-dialysis, dialysis, transplantation, chronic rejection 20 years later, redialysis, re-transplantation was beginning to be realised. We were actually getting patients to move through those compartments. Enormously challenging, tremendously exciting, we knew the sorts of things that we needed to do. We went to our hospital administrators (before trusts were invented), 'What can we do about this?' 'I'm sorry, there's absolutely no room for any initiative at all, no matter how cost effective or how clinically useful you think it will be.' Right, so we raised some money, got some legacies, and just pushed ahead. That's how we built the first interface with our path lab. It was very hard work and we young lions were up to it. That process was deeply enlightening for everybody, and I think pulled out the officer-like qualities of a lot of people who sort of selected themselves for our speciality. I don't think I'm making up a fairy tale. I think I'm right looking around, and knowing my friends in the transplant fraternity, they are exactly the same sort of people: enthusiasts. But did they say enthusiasm in the British Computer Society?

Will: No.

Sells: Exactly. Well I think, that to me is the missing element. Without that you get a whole lot of people without excitement who will say: 'Okay, give us the rule book and we'll do our nine-to-five job for which we are paid.' That is the culture of the National Health Service now.

Will: Well, the enthusiasm is incorporated, I think (being alliterative) in the 'will' to do something, which is part of 'innovation', as I understand it, or the innovation mantras. [83]

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[83] Tomson (2009).

Sells: Why do we do it? It's inside us. And, in a sense, there's deep satisfaction in knowing that this is something that I want to do and, Good Lord, I'm quite good at it. But without that, what is there?

Will: Well, I think we've brought out the fact that a lot of this was idiosyncratic energy that people applied in a particular context. Absolutely right. Terry.

Feest: I'd actually written down earlier what Robert has just said, which was selection by nephrology service. Nephrologists particularly 20 or 30 years ago were a very selected group of people. They were dealing with high tech numbers but something new and exciting. Going back to Jeremy Wyatt, it may not fulfil Jeremy Wyatt's criteria – but I would question his criteria. I don't think those are the drivers. If you asked us why we wanted clinical systems I suspect you'd get the same answers as 20 years ago and all of this is an optional extra.

Will: My purpose is being misunderstood. My purpose was to show what the cultural background to the clinical IT concept was in 1995 and how that had changed from the lack of explicit concepts in 1979, not to promote them or anything like that.

Feest: I'm not saying that, I'm saying that was Jeremy Wyatt's view. I'm not sure that was the cultural background in 1979. If you asked any of the people around this table who were practising, we'd have said: 'That's fine. But what we want is probably what we wanted in 1980.'

Will: I think I take issue with that. There's no doubt that evidence-based medicine as a movement swept through all of our clinical cultures in the 1990s. The explosion of the clinical literature, patient participation, the multidisciplinary team concern, the confidentiality issues that have come out, and the complexity of the contract are absolutely mainstream issues of today as they were developed from 1995, but they are different from where this interest started.

Feest: I'm not saying they're not mainstream issues, but if you look at what were our drivers, you accept that even in 1995, and now I suspect, that our drivers are very similar and those are issues that you add on. They are mainstream but they may not be number one, two or three.

Will: Okay, I think you've made that point. Andy.

Stein: Just to follow up something that Fergus said about the stick. I think the only way that I can see that this group is going to finish the job is if we get into bed with the commissioners, as you are starting to do. So, for example, the Renal Association's main thrust to get clinical change through IT is a programme called K-QUIP (Kidney Quality Improvement Partnership), which we can talk about later if there's time. But I feel we need to actually knock on the door of NHS Improvement and ask for variable tariffs for good haemo, bad haemo, good PD, bad PD, good and bad transplantation; like there are variable tariffs now in fractured neck of femur, for example. That has had a huge effect on the speed that people have their fractured neck of femur fixed. I've suggested this approach to a series of Renal Association Presidents who've not really bought into it; but with Graham Lipkin coming up as new President, I think there's a chance, rather than wait for the Government to come to us. In your day, you went to the Government, but I think we lack a bit of momentum. Our generation could, and we should say: 'Let's have a variable tariff' because then the money comes into the Trust and people inside the Trust would start to encourage good practice. I don't know if you've thought about that, Fergus, or if it's a subject for another day?

Will: I'm going to have problems with the edited transcript in how far we go into current NHS politics. Is there any further comment about this?

Peter Rowe: I've been a member of the Clinical Reference Group (CRG) for Renal Transplantation, which is now being amalgamated with the dialysis CRG. These issues are actually being discussed. There's a bit of nervousness about using money to bring clinicians to change behaviours, interestingly, which I'm quite surprised about. But actually this has been done already in haemodialysis;

initiating long term dialysis with access provided by an arteriovenous fistula brings in more money than if you start off with a central venous catheter. This simple tariff change has driven an enormous change in clinical practice.

The DoH has also done it with the QOF (Quality and Outcomes Framework) and the danger is that it's a temporary thing, and of course the premium is withdrawn after a period of time. But actually it's a perfectly reasonable thing to do and you're right because actually it drives the internal bureaucracy of the NHS to behave differently. So if your trust is going to get more income because you want to do something a bit differently they'll certainly decide you ought to do it and support you. This can be a powerful driver for continuous quality improvement provided it is led by clinicians and not accountants.

Caskey: I'll just add very quickly: the idea is not so much even to beat the nephrologists but it's actually to provide the nephrologists with the basis to go to the Trust, almost to give you the tools to go to the Trust, because at the moment the money is going into the Trust, and the renal unit has no way of getting that money out of the central pot of (Trust) money.

Rowe: So, if we go to them and say: 'We want to do it differently, can you please put a driver in?' they'll say: 'Okay.'

Stein: And by the way if we don't do that we won't get the higher tariff, boys and girls.

Will: Well, whether that can be solved, I'm unsure. Mike Gordon throughout has said he wasn't quite sure what clinicians wanted. My suspicion is that one of the reasons we got a poor press and couldn't publish throughout the 1980s and early 1990s was that we weren't quite sure what we were doing ourselves. We couldn't summarise it because it was, in the end, a series of qualitatively different activities that didn't hang together particularly well. I wonder if this was all to do with a certain kind of clinical experience that we had from the IT, because I think it changed the quality of what people were doing. There is a problem in how you talk about clinical experience, if you like, a rather abstract concept.[84] How can we talk about the experience, or atmosphere, of clinical practice? Keith and Mike [Gordon] tried to convey this in their paper on the 'anatomy' of the clinical system.[85] One way of taking it forward might be say: 'Yes, you can describe the anatomy but what was the 'physiology' of the system? What were the functional states?' Not just the levers and the strata, but if we're talking about an atmosphere, how do you project that, how do you discuss it? We can try and do it in data models, the granular diagrams of what goes between A, B, and C and with what product, but that is quite a remote, abstract, exercise from what the clinicians were doing. Have others here had any kind of feeling that there was a clinical experience that wasn't conveyed, and that Mike's confusion was perfectly legitimate?

Gordon: Can I make clear what I am now saying at least, if possibly not at the beginning. No, it's the same thing. I at least had a model and that model came from the fact that, prior to when I was at St Thomas', I did quite a lot of things to do with electronics and so on, which were essentially, or a lot of it had to do with, control loops – using feedback to control what happened. It seemed to me that the first thing I could understand was that dialysis was some kind of control system, in that you observe things about the patient, what was happening, and then you did something to change the input and thus get the result that you wanted. That seemed okay. My problem was that people kept telling me other things that they were doing, which I couldn't understand in that context, possibly because actually I was being a bit thick. I think that, as I said, what Conrad was putting together was much more to do with what you've called the 'physiology', and what I'm talking about really is, 'okay, there are laboratory tests and results and then there are adjustments to dialysis'.

Well, I somehow felt this applied to other areas of medicine. But then, for example, it's so blindingly obvious. I'm sure if you're a clinician it's so obvious you don't even know it's there. As I said, first Martin's project and later a diabetic unit where

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[84] The attempt to develop a high-level description of the consequences of IT has preoccupied others, of course, for example, Freidman (2009).
[85] Simpson and Gordon (1998).

I set out this work and he told me a whole lot of things about peripatetic nurses. Well, if you know how the physiology works, in other words, really how that control loop is actually implemented, it all makes sense. But it isn't sense if you've never heard about peripatetic nurses, if you've never before heard about hypertensive markers, if you've never heard about notifications sent to all your patients about flu vaccinations, all of which the system can do. But to us it was just one more thing to add to the system and it's fortunate that Conrad found a way to add it easily.

Will: The interesting thing to me is that even if you couch it in terms of physiology versus anatomy and so on, you're still at an instrumental level. You're not going to motivate clinicians by saying how exciting it will be for them to be participating in so many feedback loops. It's not going to cut the mustard.

Gordon: It will help you to understand the next unit that you come to that's talking about doing things in what appears to be a completely different way. That's from the computing side. I asked Mike Bending of Carshalton to tell me what this was all about and he just told me a lot of things about the statistical incidence of renal failure, which wasn't really what I was asking. But I didn't actually know what I was asking, that's the trouble.

Knapp: I think the way I understand it is that it is fine to make theories about what could happen if you have enough knowledge of physiology and disease, and we can all make a marvellous story, but can we produce the proof needed to get publication? The required 'proof' for evidence-based medicine is now the randomised controlled trial, with meta-analysis of others if available, and n=1 studies in single patients. Even crossover of an intervention or statistical analysis of the time series of data are not often part of the modern approach. They certainly could be generated in our computer systems, with statistical probability for an effect of a change on an individual patient. If this is how a computer system is used, would it be accepted as evidence for conveyor belt performance in industry? If you really have a need to convince people that they should spend money and effort on implementing a particular style of computing, there needs to be a look at doing trials which compare X with Y, as in my Obstetric Unit where there were alternative IT approaches for comparison and an outcome decided by an equivalent of the 'vote' of midwives![86] It is not necessary to prove that renal and other clinical units should have computers. The question is which way of using a system is best. That question might benefit from a randomised trial or by n=1 longitudinal studies. It would then remain to be seen whether providing harder evidence would make any difference to clinical uptake of IT.

Will: Keith was talking earlier about the great difficulty of motivating some people to even look at the systems and how there is some kind of resistance that runs through clinical practice in some places, and I think this is still a contemporary problem. As the hospitals digitise generally there are those that really don't want to know. How do we explain that? Because that's not to do with the instrumental; it's not how many trials that are convincing them IT might or might not work. My prejudice is that it's to do with consciousness. I think this is a slippery human dimension and it's a problem because we have never talked about what I think of as the clinical atmosphere in a unit.

We all know that when you go onto a ward or into a unit, you know straight away that it's working well and if it's not, you know straight away that it's not. One telling example is the introduction of cyclosporine in renal transplantation. Robert mentioned earlier that in the steroid-azathioprine days, haematemesis, which could be fatal, had to be anticipated, was quite common and created in the early transplant period an atmosphere of considerable anxiety in the staff.[87] It was a risky environment in which they were working. When you brought in cyclosporine, the whole clinical course slowed down. The complications became much less common, the rejection was slower and the clinical atmosphere for those working in the unit changed towards a more relaxed format. That is what happened.

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[86] See page 94.

[87] See page 37.

Robert can't discriminate that from the introduction of CCL and data management because they happened at the same time. It seems to me that there is a kind of social consciousness within those clinical atmospheres. Are you in a largely reactive situation, where you wait for what happens, you deal with it as it happens, and you simply manage it from the resources you've got? Keith mentioned the chaos in the renal unit atmosphere he encountered initially but how pluripotential clinicians managed it so well, in the way that, say, the military aspire to. If you train for chaos you can manage it; you even get pleasure from managing it. What you may not like, having refined your own professional life to dealing with chaos, is the new clinical IT, because the IT, in the same way that cyclosporine did, evens out the whole environment, allows you to know what's happening, allows you to control the reactive circumstances, allows you to plan and changes the atmosphere in which you and other are working. I find that quite a big difference. We can then talk about the consciousness of clinical work in terms of reactive and proactive components, I see this as a sort of denouement gift of the computing group, if you like. If we could formulate a description like that then perhaps that's what we can carry to those who won't engage with the IT, or perhaps we can understand some of the reasons why some of them don't. It is far from unreasonable to resent a change to the environment for which they have trained to achieve control.

Gordon: I had the experience of persuading or trying to persuade a great many departments and related people in hospitals, because by that time it was that or go under, frankly. We had to talk the Mayo Clinic's IT department out of rejecting it flatly, which in the end the clinicians did by threatening to go to a private donor; and the West Midlands, I think it was; And on and on and on. But I think there are all sorts of different reasons: there's the political structure; there are the funding barriers in the way; also, one very simple thing is, people have to see enough people it's affected to understand what it can do. The example that comes to mind is one place where we explained to the Secretary that it could save the trouble of typing out all these letters. And she said: 'Oh, that's no problem. They're all pretty much the same letter, I can just rattle them off as quickly as you like.' So I suppose there was a sort of job protection issue as well but she just didn't know that it could do it, and she didn't know what it would mean.

Will: I think my concern is that projecting the specific functional improvement that can occur, let's say doing the letters and so on, doesn't really address what will convert people to submit to, because it very often is submitting to the IT change. I'm interested to know what people think about this. Is this actually an accurate description?

Sells: I've been examining your proposition and I think, with great respect, it goes too far. I don't think we can ascribe particular changes in the satisfaction and the quality of the life of the people who do dialysis and transplantation by attributing that to anything to do with data storage and retrieval, other than the huge difference that there was between what we were doing in 1978 and what we were doing in 1995. It's very important indeed to pay some attention, as the Department of Health now understands, to the quality of life of particularly our junior doctors. And if there is an important political, if you like, effector mechanism through CCL and other types of data storage and retrieval systems, it is to enormously improve the quality of life, or the appreciation of the jobs that junior staff do, because that is the biggest problem the Department of Health has on its plate at the moment. There has been complete loss of trust. So simple access by staff to all relevant data can have a great deal of benefit – a lot of junior staff whom I've talked to recently need work stations that are mobile and they don't have them. I think that's important.

Dumler: Just thinking from the outside, about what I see, or what I saw, in the working environment of a physician as of January 2015, that's the month I retired. The first thing is, in my institution all residents are given a laptop – so we start there. The entire hospital is wired and we use a single electronic medical record, which currently is EPIC. The library is also wired so that anywhere in the place you can go and look at things. EPIC has up to date icons so you are writing a note on a patient and say you don't remember what the incubation period is for typhoid fever, you click and it tells you. So you go back and you ask the patient a variety of questions, look at things like that. There are other icons that send you to, for example, CDC's (Centres for Disease Control) latest vaccination programme, so they're all there. You can link to the American College of Physicians evidence-based practice whatever, you can pull the articles while you're doing your things.

Those kids get a laptop, they have a 15-minute introduction, and then I go and ask them: 'How do I do this? Because it is a totally different world. Now they play Pokémon at age two, they have cell phones at age five, so a lot of this barrier, although we're suffering it, is going away. The integration of the system is very helpful. Does it make their work faster? The answer is yes. I want to see the labs from last week – you can make your own panel – so I have renal panel and it shows a whole bunch of things. You click there, the renal panel comes. You have today's values, you can open it to seven days value, you just scroll around, or you can go on a graphics mode and it shows you the thing.

Will: What you're describing is a very comprehensive, proactive rather than reactive environment and yet a lot of American physicians are claiming dissatisfaction with the demands that that environment makes on their clinical practice. So with one step forward, half a step back, I guess. Is that a fair comment?

Dumler: That's correct. So for now what happened to me: I have a consultation clinic in the afternoon for outpatients and because of who I am, I put it up to 30 minutes per patient, basically because we run over time and nobody said to me: 'You cannot not do that.' But on average it's about 20 minutes. I'm used to talking to people and writing micro-notes, which then I will expand. So what happened to me is I get to practice in the same way. I have clinic from 1 to 5:30, I get home at 6, I walk the dog at 7 o'clock, I eat dinner it's 8 o'clock. At 8 o'clock I sit on my computer and I write my notes until 11:30; and then I go to bed. Then the next day I'm out to the Dialysis Unit for the 6am shift. So I didn't like the computer. The alternative was what you see in many American offices: you ask the patient 'and how are you doing today?' face to face. The rest of the time you are looking at the computer screen. So that was uncomfortable. But on the other hand, to be able to see data is absolutely fantastic.

Will: So, are there any further comments on this attempt at a high-level description of the shift that the IT made/makes to clinical practice?

Stein: I think we (or should I say you) in nephrology started a revolution in this country which everybody around this table should be proud of, and it's had a profound effect, as you know, on all of medical IT. Okay, general practice probably got going before secondary care; but hospitals, after many of you retired, are now coming into line slowly, through gritted teeth. Unfortunately, the kind of thing renal had been doing for years has not led a revolution in every speciality, but it is happening, and as has just been said, the junior doctors are making it happen. So, for example, they are choosing jobs in hospitals with better IT, where life is easier, there's less chaos. We are choosing consultants based on their IT skills and working at the Renal Registry. In the old days, vasculitis was what got you a job. The world, you know, is changing and whether we like it or not, the youth will change it for us.

Will: Very good. Well, we should draw to a close then. Mike, you had some proposals?

Goggin: I've had a quick look through the constitution and no single person sitting around this table is a member of the British Renal Computing Group because the annual subscription has been due on the 1st January every year. I could, if I was very clever, make a case that there's about 29 years of subscriptions to pay. Once the subscription has lapsed once and it doesn't get renewed, it's supposed to be my responsibility to let you know that you owe it, so let me say 'you owe nothing'. We are all not members. Apart from or observers we were all members then and the amazing thing is, we are still here. We were enthusiastic and we're still enthusiastic, and I found this a most refreshing meeting. Es has really held it together in a superb way.

And now we're going to put the transcript together and try to produce something that we hope will turn out to be useful to somebody in the future. Thank you very much for coming. I think the College of Physicians has looked after us very well

Will: Mike, we ought to thank you for all the organisation as well, and so I got you a tasteful, if not tasting, book. I understand you don't know whether it is on your bookshelves or not, but people have signed it as a mark of appreciation.

Goggin: Thank you very much for that, and I will try to use this in my future life to make better decisions about wine. [Laughter]

Appendix 1

Structure of Seminar – What and Why?

	Context, Opportunity and Motivation	Lead	Pages
1.	Introduction to the pre-1980s NHS	*M Bone	1-11
2.	Prompts to renal computing	*M Goggin	11-21
3.	Charing Cross IT development	*M Gordon	21-28
4.	Available computing potential	*C Venn	28-35
5.	IT82 and the origin of the BRCG	*R Sells	35-45
	The BRCG		
6.	The constituencies of BRCG	*M Goggin	45-55
7.	BRCG concerns and activities	*EJW	52-54
8.	The EDTA Registry and UKM	*N Hoenich	54-61
9.	Computer Support Staff survey	*B Temple	62-74
	Clinical contributions		
10.	Renal Unit IT development	*K Simpson	74-89
11.	CCL development	*M Gordon	89-97
12.	CCL User Group	*B Temple	97-106
	Circumstances and Principles		
13.	BRCG in retrospect	*EJW	106-117
14.	Modern relevance	*K Simpson	118-125

Close

Appendix 2

Contents page of *Kidney International* 1983 Volume 24, Issue 4, 433-525

http://www.kidneyinternational-online.org/issue/S0085-2538(83)X4400-0
(accessed 19 February 2018)

Guest Editors: Martin S.Knapp and William W. Stead

SYMPOSIUM ON COMPUTING IN CLINICAL NEPHROLOGY

Introduction; Computing, mathematics, and the nephrologist
Martin S. Knapp p433–435

Introduction; Evolution of technology brings computers to the bedside
William W. Stead p436–437

Computing and Mathematics in Nephrology; Selection, presentation, and interpretation of biochemical data in renal failure
D. Brian Morgan, Eric J. Will p438–445

Practicing nephrology with a computerized medical record
William W. Stead, Leland E. Garrett Jr., William E. Hammond p446–454

Experience in the computer handling of clinical data for dialysis and transplantation units
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Computerization of the medical record: Use in care of patients with endstage renal disease
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Mathematical and statistical aids to evaluate data from renal patients
Martin S. Knapp, Adrian F.M. Smith, Ian M. Trimble, Roy Pownall, Kerry Gordon p474–486

Kinetic modeling: Applications in renal and related diseases
Peter C. Farrell p487–495

Computer methods, uremic encephalopathy, and adequacy of dialysis

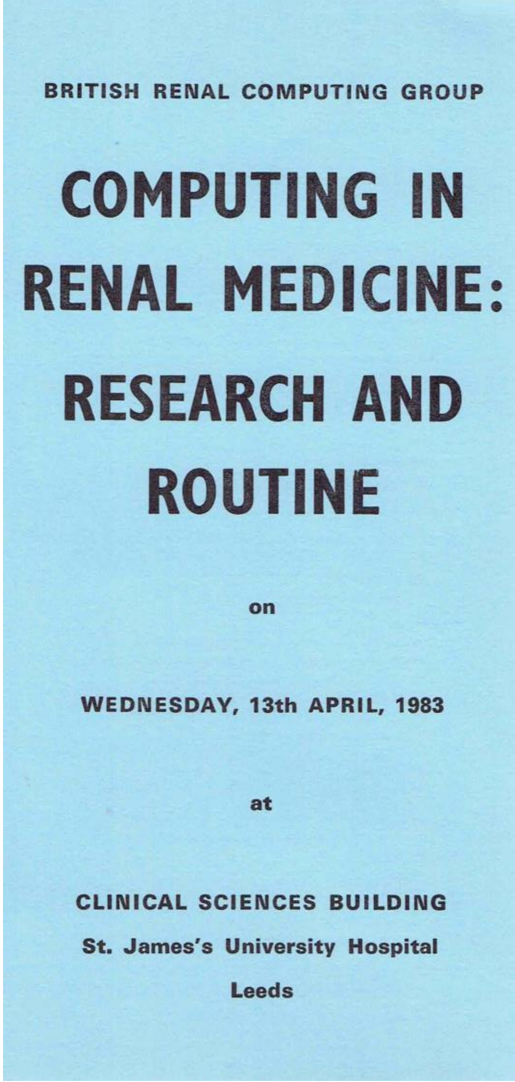
John R. Bourne, Paul E. Teschan p496–506

Evolving methodologies in computerized European Registries
Anthony J. Wing, Joe D'Amaro, Lars U. Lamm, Neville H. Selwood p507–515

Graft survival after renal transplantation: Agenda for analysis
Sheila M. Gore p516–525

Appendix 3

Programmes of the Annual BRCG Meetings



BRITISH RENAL COMPUTING GROUP

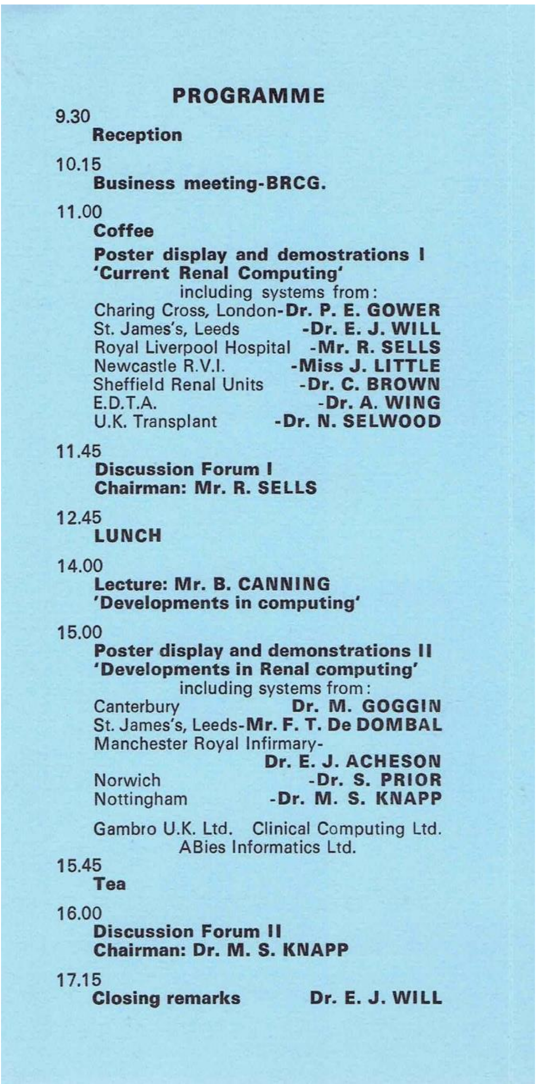
COMPUTING IN RENAL MEDICINE: RESEARCH AND ROUTINE

on

WEDNESDAY, 13th APRIL, 1983

at

CLINICAL SCIENCES BUILDING
St. James's University Hospital
Leeds



PROGRAMME

9.30
Reception

10.15
Business meeting-BRCG.

11.00
Coffee

Poster display and demostrations I
'Current Renal Computing'
including systems from:
Charing Cross, London-**Dr. P. E. GOWER**
St. James's, Leeds -**Dr. E. J. WILL**
Royal Liverpool Hospital -**Mr. R. SELLS**
Newcastle R.V.I. -**Miss J. LITTLE**
Sheffield Renal Units -**Dr. C. BROWN**
E.D.T.A. -**Dr. A. WING**
U.K. Transplant -**Dr. N. SELWOOD**

11.45
Discussion Forum I
Chairman: Mr. R. SELLS

12.45
LUNCH

14.00
Lecture: Mr. B. CANNING
'Developments in computing'

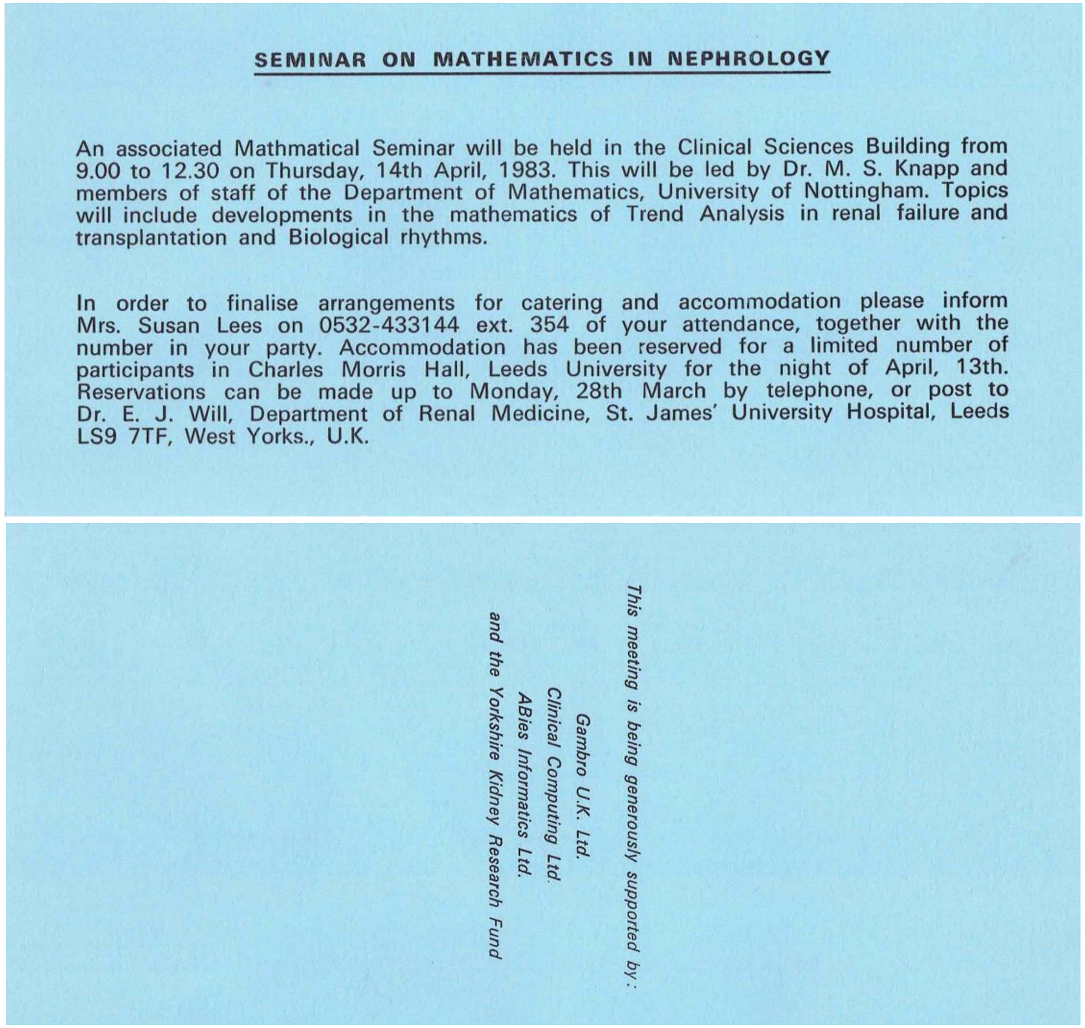
15.00
Poster display and demonstrations II
'Developments in Renal computing'
including systems from:
Canterbury **Dr. M. GOGGIN**
St. James's, Leeds-**Mr. F. T. De DOMBAL**
Manchester Royal Infirmary-
Dr. E. J. ACHESON
Norwich -**Dr. S. PRIOR**
Nottingham -**Dr. M. S. KNAPP**

Gambro U.K. Ltd. Clinical Computing Ltd.
ABies Informatics Ltd.

15.45
Tea

16.00
Discussion Forum II
Chairman: Dr. M. S. KNAPP

17.15
Closing remarks **Dr. E. J. WILL**



SEMINAR ON MATHEMATICS IN NEPHROLOGY

An associated Mathmatical Seminar will be held in the Clinical Sciences Building from 9.00 to 12.30 on Thursday, 14th April, 1983. This will be led by Dr. M. S. Knapp and members of staff of the Department of Mathematics, University of Nottingham. Topics will include developments in the mathematics of Trend Analysis in renal failure and transplantation and Biological rhythms.

In order to finalise arrangements for catering and accommodation please inform Mrs. Susan Lees on 0532-433144 ext. 354 of your attendance, together with the number in your party. Accommodation has been reserved for a limited number of participants in Charles Morris Hall, Leeds University for the night of April, 13th. Reservations can be made up to Monday, 28th March by telephone, or post to Dr. E. J. Will, Department of Renal Medicine, St. James' University Hospital, Leeds LS9 7TF, West Yorks., U.K.

This meeting is being generously supported by:

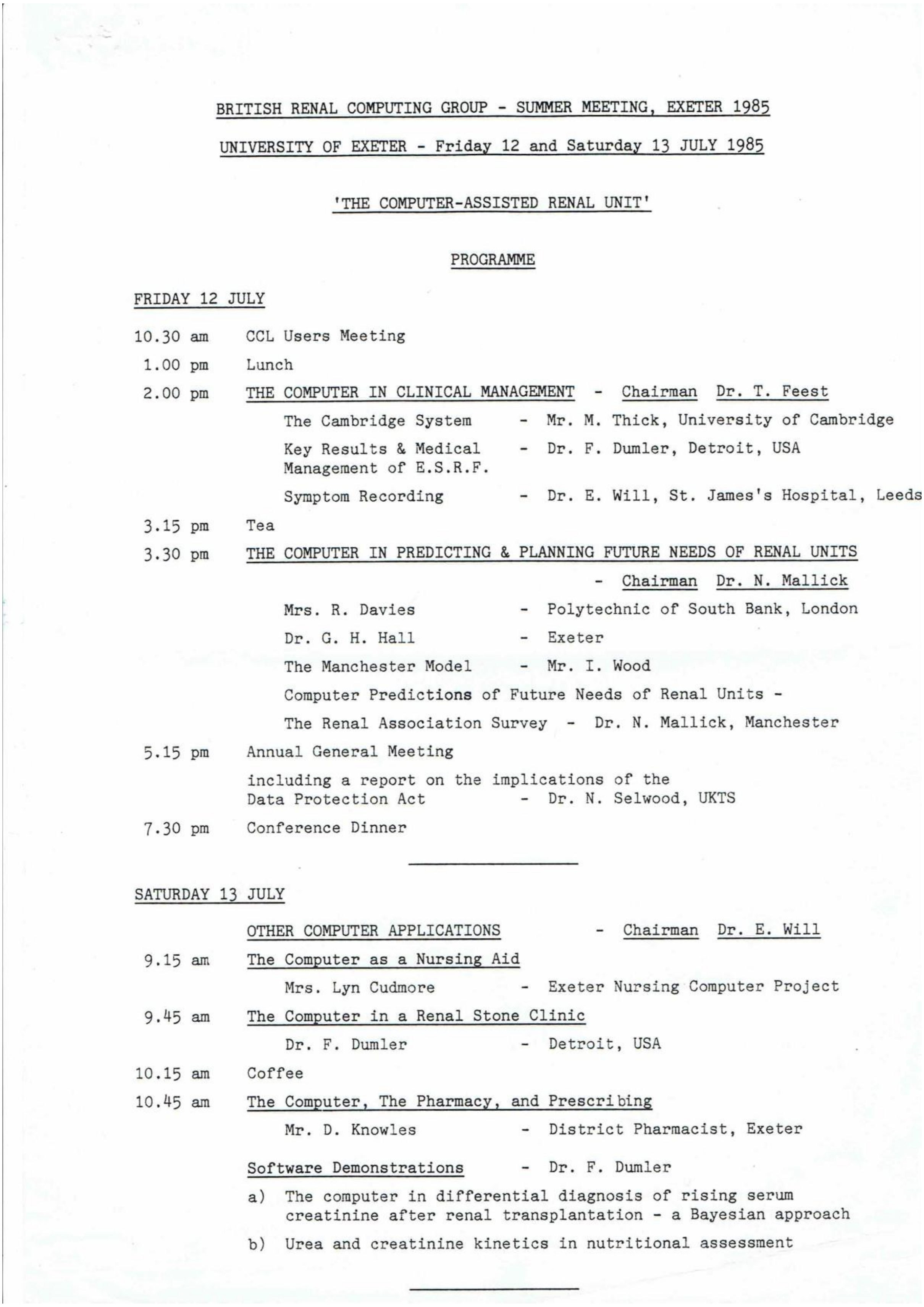
Gambro U.K. Ltd.
Clinical Computing Ltd.
ABies Informatics Ltd.
and the Yorkshire Kidney Research Fund

SCIENTIFIC & TECHNICAL MEETING - PROVISIONAL PROGRAMME

NEVIN LECTURE THEATRE, ST. THOMAS' HOSPITAL

11th JULY, 1984, AT 2.0 P.M.

1.	Organisation and Support of Mini-computing in Renal Units	
	Introduction	Dr. E.J. Will
	Developments in the West Midlands	Dr. D.C. Dukes
	An alternative approach to Medical Records	Dr. M. Goggin
2.	Experience with Multi-Databases	Miss C. Clark or Mrs. B. Temple
3.	Computer Linkage	
	Automatic Pathology Laboratory Reporting to a Renal Unit Computer	Dr. M.R. Bending
	Useful links between DEC and BBC Systems	Dr. J. Cowie
4.	Computer - people linkage	
	Closing the information loop	Dr. P. Mayor
	Hull Data: capture and review	Mr. M. Kilvington
	Computer on the Ward Round	Dr. T. Feest
5.	Basic Developments	
	Further experiences with the Kalman Filter methodology for clinical event detection	Dr. M.S. Knapp
6.	Linkage with central registries	
	The UKTS/EDTA experience	Dr. N.H. Selwood
	Computer or paper returns?	Dr. E.J. Will



BRITISH RENAL COMPUTING GROUP - SUMMER MEETING, EXETER 1985

UNIVERSITY OF EXETER - Friday 12 and Saturday 13 JULY 1985

'THE COMPUTER-ASSISTED RENAL UNIT'

PROGRAMME

FRIDAY 12 JULY

10.30 am CCL Users Meeting

1.00 pm Lunch

2.00 pm THE COMPUTER IN CLINICAL MANAGEMENT - Chairman Dr. T. Feest

The Cambridge System - Mr. M. Thick, University of Cambridge

Key Results & Medical Management of E.S.R.F. - Dr. F. Dumler, Detroit, USA

Symptom Recording - Dr. E. Will, St. James's Hospital, Leeds

3.15 pm Tea

3.30 pm THE COMPUTER IN PREDICTING & PLANNING FUTURE NEEDS OF RENAL UNITS - Chairman Dr. N. Mallick

Mrs. R. Davies - Polytechnic of South Bank, London

Dr. G. H. Hall - Exeter

The Manchester Model - Mr. I. Wood

Computer Predictions of Future Needs of Renal Units -

The Renal Association Survey - Dr. N. Mallick, Manchester

5.15 pm Annual General Meeting

including a report on the implications of the Data Protection Act - Dr. N. Selwood, UKTS

7.30 pm Conference Dinner

SATURDAY 13 JULY

OTHER COMPUTER APPLICATIONS - Chairman Dr. E. Will

9.15 am The Computer as a Nursing Aid

Mrs. Lyn Cudmore - Exeter Nursing Computer Project

9.45 am The Computer in a Renal Stone Clinic

Dr. F. Dumler - Detroit, USA

10.15 am Coffee

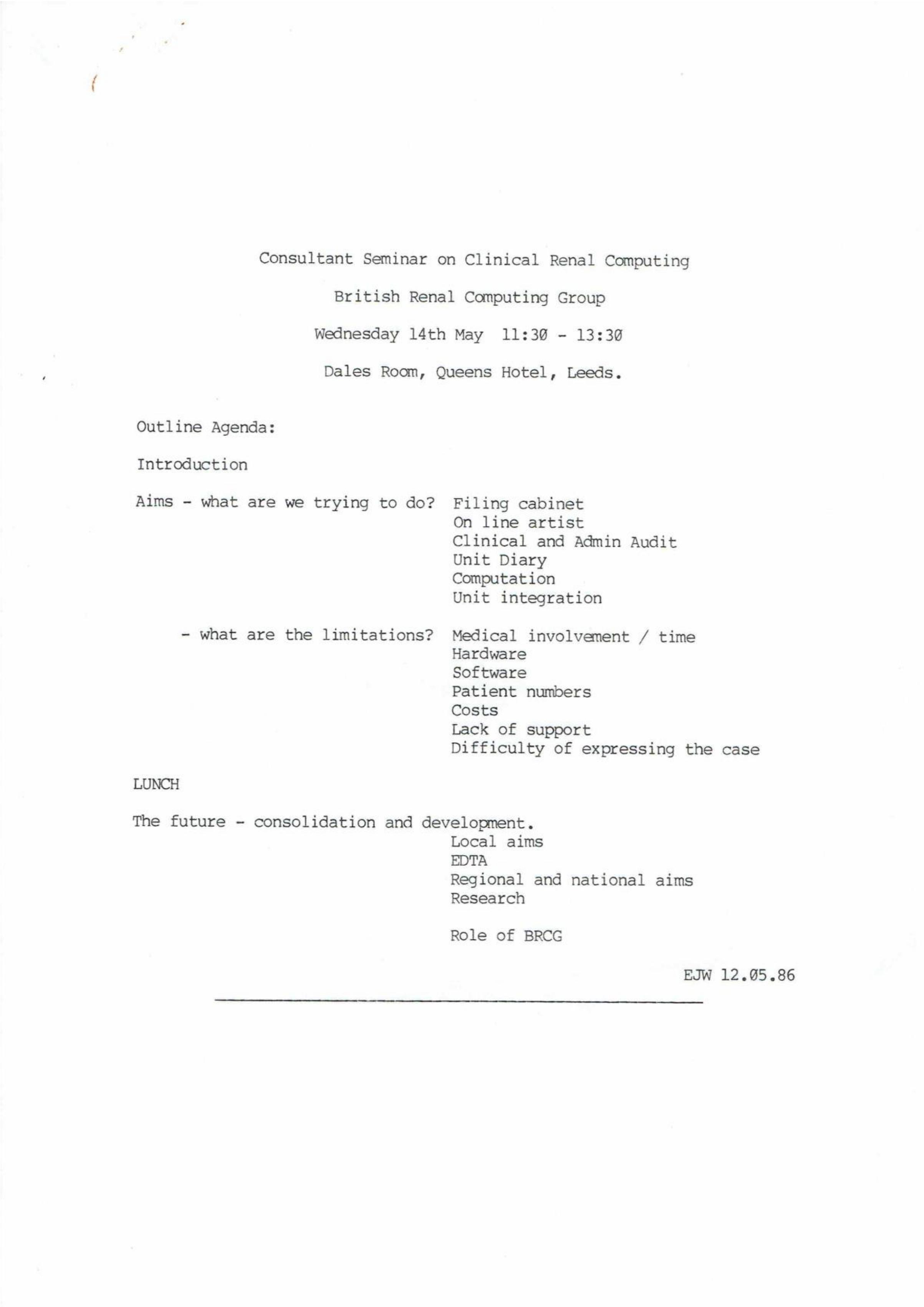
10.45 am The Computer, The Pharmacy, and Prescribing

Mr. D. Knowles - District Pharmacist, Exeter

Software Demonstrations - Dr. F. Dumler

a) The computer in differential diagnosis of rising serum creatinine after renal transplantation - a Bayesian approach

b) Urea and creatinine kinetics in nutritional assessment



Consultant Seminar on Clinical Renal Computing

British Renal Computing Group

Wednesday 14th May 11:30 - 13:30

Dales Room, Queens Hotel, Leeds.

Outline Agenda:

Introduction

Aims - what are we trying to do?
- Filing cabinet
- On line artist
- Clinical and Admin Audit
- Unit Diary
- Computation
- Unit integration

\- what are the limitations?
- Medical involvement / time
- Hardware
- Software
- Patient numbers
- Costs
- Lack of support
- Difficulty of expressing the case

LUNCH

The future - consolidation and development.
- Local aims
- EDTA
- Regional and national aims
- Research

- Role of BRCG

EJW 12.05.86

BRITISH RENAL COMPUTING GROUP

SCIENTIFIC MEETING 1986
Friday 26th and Saturday 27th September
UNIVERSITY OF WARWICK

PROGRAMME

Friday 26th September

0930-1000	REGISTRATION	
	SESSION I	Chairman: T G FEEST
1000	Current status of the West Midlands network	A K BROADMAN
1015	Computerised records of patients with endstage chronic renal failure in Edinburgh	R WINNEY
1035	The Renal Computing System and Transplantation in Liverpool	R SELLS
1050	Drug Treatment on the CDS system in the West Midlands	C YEOMANSON D C DUKES
1105	COFFEE	
1130	Laboratory linkages to the Renal System in the Manchester Royal Infirmary	J ACHESON
1150	Transplantation linkages - electronic mailing in Wales	J SALAMAN
1205	Renal Computing at EDTA, Budapest	E J WILL
1220	Development of a New Renal System at Dulwich, based on Informix	H TIMIMI D TAUBE
1240	LUNCH	
1400	ANNUAL GENERAL MEETING	
	SESSION II	Chairman: M GOGGIN
1430	The Monitoring of Cyclosporin A in Renal Allograft recipients	A HILLIS
1445	A computer-enhanced learning system	G HOMER M S KNAPP
1500	The MRC Protein Restriction Study - Computer handling	J WALLS
1515	A computer network for clinical trials in Europe	N GRETZ
1535	TEA	

1600	Simulation for planning Renal Services in Europe	R DAVIES H DAVIES
1630	Computing Clinical Needs in Nephrology	N MALLICK
1700	FREE DISCUSSION, POSTERS AND DEMONSTRATIONS.	
1900	SHERRY	
1930	DINNER	

Saturday 27th September

SESSION III Chairman: E WILL

0930 WORKSHOP: The future development of Renal Computing

Whither the B R C G?
Concepts:
    Forum for National Studies
    Contract arrangements between Units (tit for tat)
    Data handling, storage and manipulation
    Credit for initiatives and collaboration
    Relations with UKTS/EDTA/MRC/DHSS
Proposals

1030 COFFEE

1100 User Groups: I Proposed UKTS user group
II CCL user group

1230 Close of meeting

****

ANNUAL SCIENTIFIC MEETING OF THE BRITISH RENAL COMPUTING GROUP

KENT & CANTERBURY HOSPITAL, CANTERBURY
24th & 25th JULY 1987

Academic sessions at Postgraduate Medical Centre, Kent & Canterbury Hospital (PGMC K&C)

Accommodation / Social Events at Eliot College, University of Kent (UKC)

PROGRAMME

Friday 24th July 1987

12.30 Registration (PGMC K&C)

13.00 Lunch

14.00 Welcome Address: Dr. M J Goggin

SESSION I. Chairmen: F Gotch, M J Goggin

14.05 The adequacy of dialysis: a review. M J Goggin
How does urea kinetic modelling improve patient care? F Gotch

15.15 Tea

15.45 Demonstration of urea kinetic programs. M Fitzgerald
Implications of kinetic modelling for UK practice. E J Will

Panel Discussion: F Gotch E J Will
F Dumler M J Goggin

17.30 Bus leaves for UKC

19.30 Reception with Mayor and Mayoress of Canterbury, followed by dinner.
UKC, Eliot College

Saturday 25th July 1987

08.05 Breakfast

08.45 Bus leaves UKC for PGMC K&C

SESSION II . Chairman: T Feest

09.00 The paperless renal unit: dream or reality
Discussion Forum on data input methods and difficulties

T Feest B Temple
C Tomsett M Gordon

10.30 Coffee

11.00 Annual General Meeting, BRCG

11.30 Free Communications. Chairman: D Dukes

I Getting the best out of Kermit including improved functionality for CCL renal systems - CCL speaker.

II Some Quark developments - Labels & the Transition Matrix - E Will

III Unicare's Home Patient Management System - D Baldwin & S Blackburn

IV Piecewise Linear regression: a new method for detection & analysis of changes in the slope of reciprocal creatinine concentration with time - P Rowe

13.00 Lunch

SESSION III.

14.00 UKTS Users Group N Selwood

14.30 CCL Users Group

14.00 - 17.00 Demonstrations of Hardware and Software

I Informer: a portable terminal. N Selwood.

II Fitting a line to creatinine values. G Turner.

III Demonstration of the creatinine plots. P Rowe.

IV Canterbury solute kinetic programs. M Fitzgerald.

15.30 Tea

17.00 Closing remarks. M J Goggin

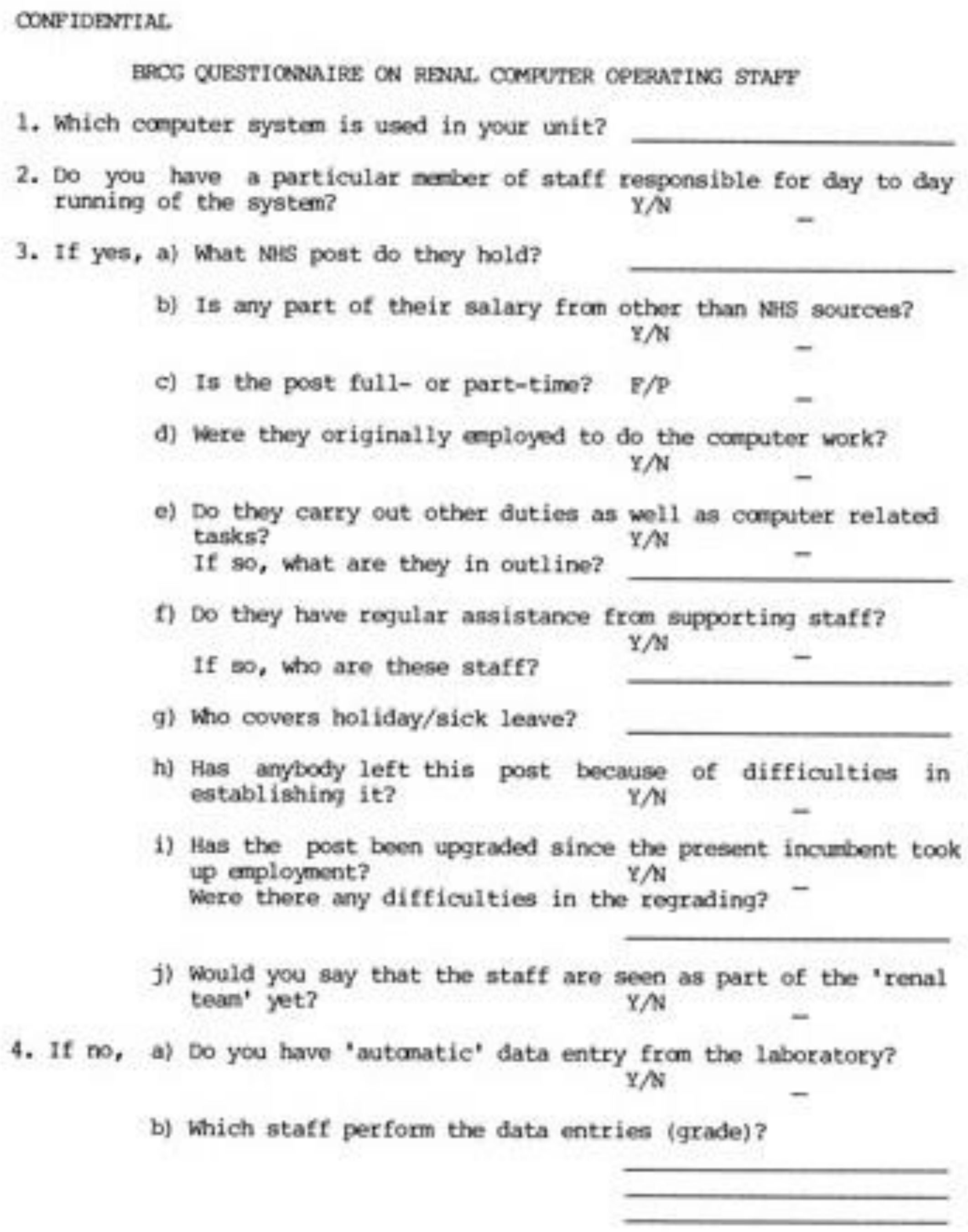
Transport to UKC will be provided for those staying overnight, 25.7.87.

Breakfast at UKC, 26.7.87 will be at 08.05.

Tel. PGMC K&C - (0227) 66877 Ext. 4360/1 UKC - (0227) 66822

Appendix 4

BRCG Computer Support Staff Survey 1985



CONFIDENTIAL

BRCG QUESTIONNAIRE ON RENAL COMPUTER OPERATING STAFF

1. Which computer system is used in your unit? ______________________

2. Do you have a particular member of staff responsible for day to day running of the system? Y/N _

3. If yes,
   - a) What NHS post do they hold? ______________________
   - b) Is any part of their salary from other than NHS sources? Y/N _
   - c) Is the post full- or part-time? F/P _
   - d) Were they originally employed to do the computer work? Y/N _
   - e) Do they carry out other duties as well as computer related tasks? Y/N _
     If so, what are they in outline? ______________________
   - f) Do they have regular assistance from supporting staff? Y/N _
     If so, who are these staff? ______________________
   - g) Who covers holiday/sick leave? ______________________
   - h) Has anybody left this post because of difficulties in establishing it? Y/N _
   - i) Has the post been upgraded since the present incumbent took up employment? Y/N _
     Were there any difficulties in the regrading? _
     ____
   - j) Would you say that the staff are seen as part of the 'renal team' yet? Y/N _

4. If no,
   - a) Do you have 'automatic' data entry from the laboratory? Y/N _
   - b) Which staff perform the data entries (grade)?
     ____
     ____
     ____

c) Which staff are responsible for screen reconfigurations (grade)? ______________________

d) Who is largely responsible for the whole system (grade)? (excluding nominal charge by the Head of Department) ______________________

REMARKS:

e.g. how do you see this staffing in the future in your unit?

Signed ....

Post ....

If you have a job description for the post in 3. above which would contribute to a national standard we should be most interested to see it. No attribution of any material provided would be made, of course, unless you desired it.

Please return by March 31st 1985 to:

E.J. Will,
Department of Renal Medicine,
St. James's University Hospital,
Beckett Street,
Leeds LS9 7TF
W. Yorks

Appendix 5

Historical Bibliography of early UK renal clinical computing

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Appendix 6

Photographs of the Participants at the Witness Seminar

Robert Sells and David Dukes

Francis Dumler, Andy Stein and Professor Mike Bone

Es Will and Conrad Venn

Mike Goggin, Robert Sells and David Dukes

Fergus Caskey, Dr Es Will, Professor Terry Feest, and Nick Hoenich

Peter Rowe, Martin Knapp and Nick Hoenich

Keith Simpson and Mike Gordon

Mike Goggin

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Participant Biographies

Professor Mike Bone

MB ChB BSc FRCP (b. 1939) studied at Edinburgh Medical school (1957–1964) and held posts at Edinburgh Royal Infirmary (1964–1975); Jewish Hospital, St. Louis, Mo. USA (1973–74); and was Consultant Nephrologist, at Sefton General, Royal Liverpool University Hospital (1975–2005). He is now retired. He was trained in Computers in Liverpool by his SHO then Research Fellow, Dr Geoffrey Taylor, and Mrs Barbara Temple. He extended the use of CCL to dialysis, then general nephrology, and clinical research. He is still struggling with Windows 10.

Dr Fergus Caskey

MB ChB MD FRCP (b. 1970) graduated from the University of Glasgow in 1993, and went on to obtain a Masters in Health Services and Public Health Research and then an MD in the Cost-effectiveness of Dialysis in Europe from the University of Aberdeen. He became a Consultant Nephrologist in Bristol in 2005 and was appointed Medical Director of the UK Renal Registry in 2013.

Through his work at the UK Renal Registry, he has broad experience and access to expertise in datasets, databases, data extraction, information governance, research ethics and the planning of analyses for audit, quality improvement and research.

His research interests include the epidemiology of acute kidney injury and all stages of chronic kidney disease, particularly around equity of access to treatment and using routine healthcare data to improve the efficiency of clinical trials. He sits on the ERA-EDTA Registry Committee.

Dr David Christopher Dukes

BSc MD FRCP (b.1935) received his BSc from Birmingham in 1958. He learned haemodialysis in Birmingham hospitals and helped to design the Minicoil artificial kidney. In 1964 he gained his MRCP, and from 1965 to 1969 was Lecturer in Medicine, at University College of Rhodesia and Nyasaland (later, University of Rhodesia) at Harare Central Hospital. He received his MD from Birmingham on

‘The Schistosome and the Kidney,’ (1969); published on tropical diseases; and became FRCP in 1974.

Dr Dukes married the late Heather Margaret Dukes (soon MB, FRCS) in 1964. She had learned vascular access surgery in the United Birmingham Hospitals as a final year medical student. Together they established haemodialysis in Harare, and also in Coventry on their return to the UK, where he was appointed as a General Physician with an interest in Nephrology in 1969.

The need for computers to handle accumulating medical data was recognised in the early 1980s. Dr Dukes and Keith Boardman, Medical Physicist, approached Mike Gordon, who installed a CCL system in the Renal Unit in Coventry. This led to Renal Units throughout the West Midlands installing clinical computers and joining the British Renal Computing Group. He was the local organiser of the national meeting of the BRCG at the University of Warwick in 1986.

Professor Francis Dumler

MD FACP FASN (b. 1945) graduated from medical school in his home town (Lima, Peru) in 1971. After a clinical clerkship at Johns Hopkins, he completed Nephrology training at Henry Ford Hospital (Detroit, Michigan). At retirement (2015), he was Chief of Nephrology & Professor of Medicine at Oakland University William Beaumont School of Medicine. He has authored 114 manuscripts, 15 nephrology chapters, and 259 meeting presentations.

Requiring a word processor, Dr Dumler self-learned CPM/BASIC. He then coded applications to calculate renal functional parameters, aminoglycoside dosing, estimates of the rate of renal function decline, and risk analysis for nephrolithiasis. As computer labs and industry were exploring rule-based expert systems in multiple applications, he developed an educational tool using a rule-based system (Differential Diagnosis of Secondary Hypertension) and a Bayesian model (Acute Loss of Renal Function in Renal Transplantation). With the rapid growth of the dialysis population, the integration of best practice protocols, monitoring quality of care, analysis of outcomes data, and uploading specific data required by health authorities became paramount. Dr Dumler was part of the team that developed The Henry Ford Nephrology Information System to fulfil that need.

Professor Terry Feest,

MA MB BCh MD FRCP (b. 1944) is a retired consultant nephrologist. He qualified in medicine in 1968, and his first consultant appointment was to Exeter in 1978, where he installed a renal IT system in 1980. In 1991 he moved to Bristol, where for 15 years he was Clinical Director of the Richard Bright Renal Unit. He retired from clinical work in 2010. His long-term interests include renal tubular disorders, the epidemiology and provision of treatment for renal failure, and the audit of the quality of renal care. As well as being a member of the BRCG, he was founder chairman of the Renal Association UK Renal Registry (1995–2007), a member of the appraisals board of NICE and a clinical advisor to the National Kidney Federation. Recently he has been Director of the UK Renal Registry but is now fully retired.

Dr Michael James Goggin

MB BS MRCS FRCP (b. 1934), was in general practice in Lambourn, Berkshire (1960–1964), then held posts as Registrar at Mount Vernon Hospital (1964–1966); Cardiac Registrar at Harefield Hospital (1966–1968); Registrar and Lecturer at the Institute of Urology and Nephrology (1968–1971); and Consultant general and renal physician at the Kent and Canterbury Hospitals (1971–1995).

His clinical renal computing involvement included the transfer of manually entered dialysis data into a computer system with linkage to laboratory results, enabling dialysis adequacy to be displayed. Information available hospital-wide and linked to remote satellite units; urea kinetic modelling techniques applied to test bespoke dialysis schedules; and voluminous end stage renal failure patient records transferred to Problem Orientated Medical Record format to make clinical issues more prominent, linked to hospital administration system. He developed a simulated home dialysis machine; stand-alone computerised dietitian, parenteral nutrition and stone risk analysis systems both on minicomputers and programmable calculators; and determined intrarenal isotope transit times using gamma camera data manipulation.

Mr Mike Gordon

(b. 1937) has degrees in Physics from Cambridge (1958) and London (1963). After graduating in 1958 he worked on the first UK satellite ground station, and in 1964 joined the electronics group at St Thomas's Hospital where he developed an interest in computers. In 1971 he became a systems analyst at Charing Cross Hospital for one of the earliest PAS systems. In 1973 he joined the Department of Medicine as Lecturer in Computing, under Prof H E de Wardener, to develop a computerised record system for the hospital's renal unit. The project was successful and in 1979 with the Professor and Conrad Venn, he formed Clinical Computing Ltd to redevelop the software for more general application. The new system, Proton, was subsequently adopted by most UK renal units and the UK Renal Registry, and by centres in other European countries, in the US and the Antipodes. The adaptability of the software led to its take-up in a number of other specialties, principally diabetic and obstetric units.

Dr Nicholas Andrew Hoenich

PhD (b1946) is an Associate Member of the Institute for Cellular Medicine at Newcastle University. Prior to this he held a lectureship in Clinical Science, to which he was appointed in 1980. He was responsible for a clinical evaluation programme concerned with the performance of dialysers and dialysis machines. The data generated from this work contributed to the Urea Kinetic Modelling module developed by CCL. Dr Hoenich has had a long-term interest in the technical aspects of renal replacement therapy, focusing on haemodialysis systems and water treatment infrastructure. He has published extensively on the technical aspects of renal replacement therapy and is the author of over 130 peer reviewed articles and opinion pieces. In addition, he has written chapters in a number of texts dealing with renal replacement therapy

Dr Hoenich is on the editorial boards of a number of journals dealing with Artificial Organs and is Chair of the Working Group of the International Standards Organisation Technical Committee (ISO/TC), with specific responsibility for renal replacement, detoxification and apheresis

Dr Martin Knapp,

MB ChB MD FRCP (b. 1935) qualified at Bristol in 1959, holding appointments in Bristol, London and Duke (USA), before being appointed Lecturer in Medicine at Bristol. He received his MD (Bristol) in 1967, using the University main-frame computer for data analysis. He established renal units in Bristol in 1967, in St Louis, USA, and in Nottingham in 1970. He introduced to Nottingham the CCL renal data management system (the first commercial installation) and added on-line statistical monitoring. Subsequently his research group studied chronobiology in medicine, especially cell-mediated immunity. With local statisticians he developed Bayesian methodology for monitoring renal transplants. He convened meetings of UK nephrologists to discuss renal computing prior to the formation of the BRCG. In 1982 he represented Health Professions in the East Midland's Committee for Information Technology Year. In 1982 he established, within the University of Nottingham, an IT Unit to further develop clinical applications of computing. In 1983 he was co-editor of a Kidney International Symposium on Renal Computing. In 1988 he left UK, working in physician appointments in Australia, initially at the Austin Hospital, Melbourne, where he assisted with the integration of graphics into computer-generated discharge summaries, and later in several regional locations – including the University of Tasmania - until retirement in 2015.

Dr Peter A Rowe

MB ChB MD FRCPS (Glasgow) FRCP FHEA (b. 1956) trained at Bristol University and graduated in 1979. Following general training as a senior house officer in Exeter (1981) he then continued higher training in renal and general medicine in Bristol (1984) and Nottingham (1985). He was Senior Registrar in renal and general medicine at the Western Infirmary in in Glasgow (1989) until his appointment as Consultant in Plymouth in 1995, where he is Deputy Medical Director, Consultant Nephrologist and Honorary Associate Professor in Medicine for University Hospitals Plymouth NHS Trust and Plymouth University Peninsula School of Medicine and Dentistry.

He is a member of the British Transplantation Society, Renal Association, European Renal Association, American Society of Nephrology, International Society of Nephrology and the European Society for Transplantation.

He has practised both as a nephrologist caring for patients with all types of renal disease, and receiving dialysis, and as a transplant physician. His research interests have included both clinical and scientific aspects of renal transplantation. He has a complementary interest in computing and has developed a number of clinical applications of commercial software.

Professor Robert A Sells

MB BS FRCS FRCS (Edin) (b. 1938) trained at Guy's Hospital London and worked as a research fellow with Professor John Butterfield on blood sugar control in diabetes. After training in General Surgery, as Lecturer in Surgery he assisted Mr Frank Ellis in setting up the transplant unit at Guy's under the leadership of Professor Stewart Cameron. In 1965 he joined Sir Roy Calne's Cambridge team developing liver transplantation in partnership with the King's College London Liver team (Professor Roger Williams). Subsequently he spent a year at Harvard University working with Dr Francis Moore at the Peter Bent Brigham Hospital. In 1971 he became Foundation Director of the Sir Peter Medawar Transplant Unit at the Royal Liverpool University Hospital and was granted a personal Chair in Transplant Surgery by the University of Liverpool. His research interests include Transplantation of kidney and pancreas in diabetics with ESRD and developments in clinical immunosuppression.

Dr Keith Simpson

BSc FRCP (Glasgow) (b. 1952) is a retired Consultant Nephrologist. He is employed as a part time medical advisor to the UK Renal Registry and is currently working on the UK Renal Data Collaboration, which will improve the availability and utility of data from the UK renal community for patients, clinical care, research, quality improvement and service planning. He helped to set up Renal Patient View (RPV) and is a member of the RPV and the Rare Renal Disease (RADAR) boards.

He is a member of the UK Renal terminology committee; past Chair of the Scottish Renal Registry and member of the UK and ERA-EDTA Registry committees; he chaired the ERA-EDTA Registry Coding and Definitions Working Group until 2012 and now sits as an ordinary member. He represented the Academy of Medical Royal Colleges on the NHS Data Standards Group.

Dr Andrew Stein

BMBS B Med Sci MD MRCP (b. 1961) had renal training in Cardiff, Adelaide (Australia), Leicester, South Thames (London) and Coventry. He is a Consultant in Renal and General Medicine at UHCW, Coventry, Honorary Clinical Lecturer in Medicine at Warwick Medical School (and Undergraduate Lead in Nephrology), and a Clinical Commissioning Lead (Secondary Care) for the Coventry and Rugby Clinical Commissioning Group (CCG). In this role he is joint lead for their referral advice website, the Coventry and Rugby GP Gateway. In March 2014, he was elected to the Executive of the Renal Association.

His renal interests include pre-dialysis care and diabetic renal disease, and his general medical interests include the use of IT in medicine, health community patient flow, and the use of ambulatory care clinics to support the general medical take. He established one of the first daily ambulatory care clinics in the UK in January 2004.

With his co-author, Janet Wild, he has published four books; one (*Kidney Failure Explained*) is on its fifth edition and has won three BMA book awards. With colleagues, he runs a website, http://www.renalmed.co.uk/, and used to run another http://www.acutemed.co.uk/. In 2104, again with Janet Wild, he published an e-book, *Kidney Failure: the Essentials*.

Mrs Barbara Temple

(b. 1936) With no formal qualifications, she was the lynchpin of the Liverpool CCL computer system from its initiation, serving medical and surgical nephrology. She was the founder and Lead of the CCL User Group (after 1983), and the Lead on the BRCG survey of national renal computer staffs 1985. The CCL User Group of system managers met regularly at different venues around the country for ten years, to support each other, exchange developments at individual sites, discuss the support and training sessions available to them from the soft- and hard-ware companies, and invite relevant computer demonstrations.

Mr (James) Conrad Venn

BSc (Eng) ACGI (b. 1958) graduated from Imperial College and joined the Department of Medicine at Charing Cross Hospital as Computer Programer in 1977. He worked with Mike Gordon and Professor Hugh de Wardener, developing a system for the hospital's renal unit. He was joint founder of Clinical Computing Ltd. (CCL) in 1979, becoming their first employee in 1981; he began work to redevelop the software for more general use, under the name Clinical Data System (CDS), on DEC PDP-11 mini-computers. He started the development of Proton software in 1988 starting on IBM PCs and Novell networks, porting to VAX/VMS and several Unix variants, notably HP-UX, IBM-AIX, Sun and Linux.

He was involved in development of a Windows version from 1994 and in 2000 was Chief Architect of Clinical Vision 4 software, subsequently ported to a Web platform as Clinical Vision V.

Dr Es Will

MA BM FRCP FBRS (b. 1945), a retired renal physician, was educated at New College, Oxford (1963–66) and Guy's Hospital (1966–69). Following clinical training at the Whittington Hospital and Nottingham, he was Lecturer in Medicine, Nottingham (1974–77); Research Fellow in Leiden, The Netherlands (1975–77); Senior Registrar in Nephrology, Nottingham (1977–80); and Consultant Nephrologist, St James's University Hospital, Leeds, UK (1980–2007).

He was Chairman of the British Renal Computing Group (1982–88); Chairman of the Renal Medicine Speciality Working Group NHSCCC (Clinical Terms [Read Code] Project); National Renal Medicine Representative for Casemix; and Secretary of the UK Renal Registry (1997–2007). His research interests included renal stone disease and the kinetics of calcium oxalate crystallisation, dialysis techniques and kinetics, psychosocial aspects of renal disease, clinical computing and the theoretical basis of clinical intervention, especially in the decision support of managing renal anaemia.