

insulin levels and reduced high density lipoprotein (HDL) levels. This suggested that they may have a form of 'syndrome X', described by Reaven, of increased insulin resistance with increased cardiovascular risk. Indeed, in a long-term follow-up study by Dahlgren [3] of women who had had wedge resections for PCO, hypertension was three times as common as in controls and the estimated risk of myocardial infarction over six times higher. Professor Jacobs' report of his own long-term follow-up study concerned 1,028 women with a histological diagnosis of PCO made at surgery prior to 1970 who were identified from pathological records and followed in the NHS registry until death, age 75 or 1994, whichever came first. Their average age at diagnosis was 25.7 years and duration of follow-up 28.1 years; 82% of the records were traced. To his admitted surprise, the risk of death, and in particular cardiovascular death, in this large PCO group was the same as that expected for the population as a whole, with a trend in favour of survival in the PCO group! Professor Jacobs suggested that the higher oestrogen levels in PCO women may be responsible for changing the outcome from that predicted by the surrogate markers of cardiovascular risk (HDL etc).

Concluding comments

The conference was well attended through all four days by consultants and junior doctors, a number of them from Europe and the USA. Everybody came away with useful facts for present practice and with exciting views of the future. Fourteen junior doctors and thirteen medical students were also able to attend the conference through the generous support given by the Foulkes Foundation. One student suggested that many of her colleagues were turning away from the thought of pursuing careers in hospital medicine/research even as early as the third undergraduate year. The 54 speakers at this conference showed that we are not yet short of successful scientist-clinician role models in Britain.

References

- 1 MAAS Investigators. Effect of simvastatin on coronary atheroma; the Multicentre Anti-Atheroma Study (MAAS). *Lancet* 1994;344:633-8.
- 2 Scandinavian Simvastatin Survival Study Group. Randomised trial of cholesterol lowering in 4444 patients with coronary heart disease: the Scandinavian Simvastatin Survival Study (4S). *Lancet* 1994;344:1383-9.
- 3 Dahlgren E, Johansson S, Lindstedt G, Knutsson F, *et al*. Women with polycystic ovary syndrome wedge resected in 1956-65: a long term follow-up focussing on natural history and circulating hormones. *Fertil Steril* 1992;57:505-13.

Clinical computing: friend or foe?

A conference on various aspects of clinical computing was held at the Royal College of Physicians on 23 January 1994. The aim was to draw together experts in the field to review current progress and experience, showing the benefits for patient care, education, training and research. Systems currently in use were reviewed and their benefits and problems outlined. It was hoped that this would inspire those not currently using such systems and help them avoid the pitfalls of those with previous experience.

The conference was opened by Sir Leslie Turnberg who stated that clinicians had previously been reluctant and slow to take advantage of new computer technology. He thought that this might be due to two reasons, first that too much had been claimed for systems and they had failed to deliver these promises and second that system failures had put people off. Recently, however, there had been huge increases in computing power, combined with decreasing costs and increased computer literacy. He felt that we were on the brink of changes in attitude.

Dr J D Read (NHS Centre for Coding and Classification, Loughborough) spoke on terming, encoding and grouping. He pointed out that the importance of information was increasing and that the management dataset should be an expansion of the clinical dataset. Currently the patient record could be encoded to form clinical datasets and management datasets, eg ICD-10/OPCS 4; these could then be formed into groups, eg health care resource groups, for costing purposes. Read codes are a dictionary of clinical terms that attempt to use natural clinical language. They can also be used to record symptoms, test results and patients' skills and functional abilities. ICD-10/OPCS 4 follow definitions of conditions. The latest version of Read codes relates to ICD-10 via a 'coding frame', which allows the Read code to be encoded. A Read code may lead to more than one ICD-10/OPCS code, but will produce a default ICD-10/OPCS code that may only be altered with the addition of extra detail; eg if a 25 year old hypertensive becomes pregnant, Read codes allow this to be essential hypertension, whereas ICD-10 changes the diagnosis to hypertension of pregnancy.

Dr O H B Gyde (Birmingham Heartlands Hospital) outlined the ways in which standards were set. They may be issued by authorities, bodies or institutions,

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may be set by consensus (ie a lack of sustained opposition) or may be sets of guidelines of desirable features. There are various national and international bodies that set standards, eg British Standards Institute (BSI), International Standards Organisation (ISO). The European standards group CEN is responsible for standards that should be of interest to working doctors such as information models and medical records, knowledge and record bases, medical devices and device interchange. The group produces an interim report on the subject which is then made into a first working draft (or pre-standard) and is then voted on by the member states. He felt that standards should promote clear communication and should promote quality. Physicians should set the standards for computer based systems but they need not be the computer experts. Standards will have to be set for quality, data and coding, network connections (is it portable across the various operating systems?), data safety, software portability (will it travel from country to country and into the future?), and the human-computer interface (VDUs, keyboards, similar data entry screens for similar types of data). There are currently problems with agreeing on standards for free-text. Standards for the purchase of systems should be carried out by self-reported questionnaire and by agreement with NHS buyers. Guidance and training on the use of systems should be handled by local information management and technology sections and such training should be from the bottom up.

Dr J C Wyatt (Imperial Cancer Research Fund, London) reviewed data safety. He stated the requirements for high quality data, viz: they should be correct (complete, accurate and relevant), usable (retrievable at the right time and place, instantaneously) and should respect the patients' right to privacy. There are several threats to data. The first of these is data capture. There are problems of varying severity from confusion due to unclear definitions to falsification of data. Errors in data entry occur at a 4% mean (range 2–10%), increasing with the number of options available to the operator. Speed of entry has no effect and neither does training. Strategies for ensuring high quality data gathering include sharing out data entry, providing incentives for good quality data, integration with other systems to minimise duplication of entries, interactive terming and coding and systems to allow for the detection and correction of errors. Good quality software should ensure that data can only be entered within specific ranges and checks across data fields can be made (eg women cannot get carcinoma of the prostate). The second area of threat is to data storage through either the hardware or the software. Data integrity should be preserved by backing up at least daily and a 'full audit trail' should be used so that data cannot be deleted once entered, although they may be withdrawn from use. Hardware should have a continuous power supply and should be fault tolerant. If a net-

work is being used, it should have multiple connections, to ensure that a single terminal failure does not stop the system. The third area of threat is transfer. Copying data is easy, as is remote access. Computers also lack the 'perverse security' of the complexity of paper systems. There are a number of ways of preserving confidentiality. Physical access to areas containing computers may be restricted, as may access to the hardware and software. Different users may have different levels of power within the system, eg viewing data, editing and printing. Access to terminals may be monitored by the system. Data may be encrypted and print-outs should be shredded. Authorisation may occur by a number of means, varying from the common password, PINs and cards to unique characteristics such as voice, signature or retinal vessel pattern. A further technique of public key encryption is being evolved, whereby the sender encrypts a message, but only those with the appropriate key can decode it. It was emphasised that there were various 'hot spots' for data safety, people with specific diseases (AIDS, psychiatric diagnoses), those who had specific procedures (termination of pregnancy, paired organ surgery), specific patients (VIPs, staff members, common names) and specific clinical settings (emergencies, the unconscious patient). There is no technological 'magic bullet' for data safety and most of the problems that do occur are human.

Professor J G Williams (University College of Swansea) described the benefits and challenges of the GeneCIS (generic clinical information and management system). This employed one core structure, but allowed different sets of details to be viewed by different sets of users. The problems that the system was designed to solve were that information about patients and services was often not available and what was available was incomplete, in an unusable form or of questionable validity, eg there was a consistent under-recording by 30% of endoscopies by central departments throughout Wales. Data that were collected were also insufficiently flexible to meet the needs of differing users. The solution was to collect demographic, administrative and clinical data according to need and context. The data could subsequently be customised, methods of data entry varied to suit the user, eg limiting the input options for assessment scales and outputs customised to meet the needs of the various users. Thus far the system had been used in a variety of systems—gastroenterology (inpatients, outpatients and day cases), care of the elderly, diabetic outpatients and urology inpatients. There are various forms of output. Individual letters can be generated for patients' notes as well as GPs, activity can be analysed and output can be linked to other operating systems such as Microsoft Windows. Changes in disease activity in a single patient can be charted, referrals can be analysed, the workload of any doctor can be viewed and waiting times can be analysed. There are a number of benefits: the consultant had better information

about individual patient management, audit and service planning, such information being less frustrating and more efficient to use; patients received better decisions, waiting times were reduced, and multiple investigations were avoided; a knowledge base was built up which could be of value to GPs, who also benefited from the speedier completion of discharge summaries (93% in less than 72 hours post-discharge in the case of care of the elderly). The knowledge base also allowed for better epidemiology and support for specific studies. There were a number of important points to be made about planning for the system: the strategy should be shared and agreed between clinicians and managers; implementation should be slow according to need and enthusiasm; the task is always greater than anticipated and consequently time should be devoted to establishing the requirements; skilled support is necessary to make the system run smoothly; if contracting is the sole means of driving information technology (IT), then clinical systems are stifled.

Dr E J Will (St James's University Hospital, Leeds) spoke on the Proton Renal System, a commercial system used for a numerically stable, limited population with a limited number of processes but a large number of attributes. The system had been operating for 13 years. It functioned as a patient review system with the capacity for organising tests, treatment and medication as well as helping with quality assurance, reporting and audit. Developments during the period of use included backfilling of data from the European Registry and computer links to laboratories and dialysis equipment within the department. Modem links had been made to other departments and subsequently abandoned, showing that progress is not inevitably sustained. Software had been developed by inclusion of drug modules and Read codes, enquiry configurations had been enhanced and the increased power of computers had allowed individual dialysis requirements to be calculated. Several procedures had also been introduced including a paperless clinical record and secretarial applications. Over the years, clinical judgements by the team had given rise to protocols which have been used by the junior staff and it was hoped that this would be an ongoing procedure. The friends of IT are functionality and security, while its foes are the cost of capital and maintenance and the fact that IT allows an increase in the size of a unit, thereby decreasing consultant control.

Dr R J Young (Hope Hospital, Salford) talked about the Salford Diabetic System which has been in operation for three years. The system was founded on the rationale that effective primary and secondary health care can markedly reduce the adverse effects of diabetes mellitus (DM). The plan was therefore to develop a system that incorporated the guidelines of the St Vincent declaration and took account of the fact that diabetic care was distributed, multidisciplinary, complex and lifelong. The system therefore needed to be population based, show key indicators of service

effectiveness as output using intermediate measures such as blood pressure, and final indicators such as blindness and chronic renal failure. It had to be computerised to be practicable and available. The dataset incorporated demographics, risk behaviours and DM characteristics, ie the casemix. The output is displayed on a single sheet of A4 at the GP's request. Data gathering is based on a lifelong annual review where handwritten updates can be used to bring the record, and thence the computerised database, up to date. Laboratory reports can also be downloaded. The annual review generates a patient status form which can be given to the patient. It also generates pre-appointment testing and post-attendance recommendations. GPs can be given data on defaulting patients and the prevalence of DM in their practice and this can be compared with other practices. The system has allowed for an increased incidence of structured preventive care for specific groups such as adolescents. The system has been a success. It is appropriate to its purpose, it is acceptable to the user, it is confidential between primary and secondary care as the patients carry the records. It has also been achieved within existing organisational structures and is affordable. Dr Young finished by saying that the keys to success have been clarity of purpose, good preparation, project management, people (the system has helped them to work better) and an appropriate pace of implementation.

Dr C F A Pantin (North Staffordshire Hospital, Stoke on Trent) described his experience as a respiratory physician. In a large district general hospital with many departments, there is a need for each department to know its own business and to have appropriate information to support patient care, support services, education and audit and administration. In his practice, computers have been used to make equipment tracing more efficient; they have also allowed the more rigid use of protocols for oxygen concentrators. Patients have been allowed to enter their symptoms. He commented that staff other than clinicians thought that they were wonderful, but that doctors still preferred to write. It is necessary to balance the benefits gained against the time taken to enter and process data. Such information gathering is not cheap—ICI spends 15% of turnover on information. A computer is an information handling tool with the major benefit of stored data. Before investing in IT, it is necessary to know one's own business and to know where it can help. Data entry planning is vital and unless data entry takes place immediately it never will.

Dr R P Knill-Jones (University of Glasgow) reviewed 25 years of experience with GLADYS (GLASgow system for diagnosis of DYSpesia). Dyspepsia was chosen because precise diagnosis is difficult, there is often more than one diagnosis and the history is very important. Patients were selected from GP surgeries and out-patient departments (OPDs). Patients thought that the computer (a teletype in 1970) was as favourable as a

recorded voice and admitted to higher levels of alcohol consumption than they would to a human interviewer. They also attributed to the computer 'human' characteristics such as understanding and waiting for an answer. There were a number of problems with the patients' definitions of terms. The computer produced 40% more positive answers as it coded 'possibly yes' as 'yes'. There are several factors that produce a successful system. The interface should be simple; touch screens are preferred to 'mice'. Vocabulary should be kept simple; a reading age of 12 (roughly tabloid newspaper standard) should be assumed. The computer should give positive feedback and should allow for qualifying answers. There had been difficulties with designing questions and with obtaining diagnoses and actions following the consultation as this had meant chasing notes. In the future, there should be advances with standardising data and systems allowing the setting up of investigations prior to a consultant visit. Systems should become more portable, allowing GPs to use them. Patients may be able to interrogate the computer about investigation and treatment allowing a two way exchange of information. On questioning, he admitted that 5–8% of those asked had refused to participate in Govan in 1970, probably due to illiteracy.

Professor F T de Dombal (University of Leeds) discussed the role of computers in continuing education and decision support. The lessons learnt from one system were of general interest. He had been interested in the management of the acute abdomen which affects 2–3 million people per year in Europe, costs 1.5 billion ECUs and has a low diagnostic accuracy. The system to aid in diagnosis had been developed over 25 years and had been derived from a knowledge base involving 500 clinicians. It was emphasised that this was a comparative database and not a form of artificial intelligence. Data collection was structured. The system was tried out on 16,000 patients and increased the accuracy of initial diagnosis from 45% to 65% compared with baseline studies. Perforation of the appendix before removal dropped from 23% to 11% and negative laparotomies from 9.5% to 5.6% [1]. He asked, if the results of the study were so impressive, then why was the system not used more widely? He felt that unreasonable prominence had been given to other studies. The most cited of these [2] had used a series of 6,000 patients with no baseline for comparison. The system used had disallowed any gynaecological diagnosis and only 15% of eligible patients had been recruited during the study period. As funding for future developments had not been forthcoming from within the NHS, he had gone to the European Union and the World Organisation of Gastroenterology. The performance gap between what could be and what is being done was increasing, but ground could be regained as long as the evaluation of systems was good, poor evaluation being a major hindrance to development. During the discussion Professor de Dombal said

that he felt that there was too much reliance on randomised controlled trials to the exclusion of sequential outcome based studies.

Dr P Lelliott (Research Unit, Royal College of Psychiatrists, London) focused on points to look for when selecting a clinical system. The existing hospital information system (HIS) was inadequate for most clinicians' information needs. The NHS Management Executive states that information will be person based and that information will be derived from operational systems and not just management systems. The fact that existing systems are largely administration based has put many clinicians off using them despite the fact that they have incorporated large numbers of high technology procedures into their practice when they have seen a need. The clinicians should be the customers for clinical information as they are the users. This contrasts with many information systems in which the user has no power to interrogate the system. Many of the most successful information systems are those that are used by GPs, as most GP practices are small business run by clinicians. This means that the clinical workers see a need and are allowed to develop the system which may then develop a secondary administrative role. He outlined some of the projects currently being developed. These include the clinical-terms project discussed earlier in the day. The integrated clinical workstation project is developing an attractive interface which is intuitive and readily adapted to the place of work, eg hospital/GP. The electronic patient record is moving towards a paper-free hospital. The enabling clinical systems project is ensuring that all the projects can come together to give a coherent output. The obstacles to information systems are a top-down information strategy with procurement controlled by the managers; the complexity of the clinical process with large numbers of environments; and inadequate technology, although this is improving rapidly. The key points to look for when choosing a clinical system are: it should allow for storage of data in various formats, with linkages between clinical settings, allow cross checking across data fields, and also have spare data fields for future developments; it should be secure and be easy to use, with an intuitive screen layout; the system should be able to function as a user aid with word processing, statistical functions, diary and flagging facilities; there should be support for audit and research with the ability to support administration and contracting; the supplier should be of sufficient size to offer adequate training and support; cost should be kept as low as possible, but systems do not come cheaply.

Dr G J Hughes (Health Care International, Clydebank) gave a description of how a hospital could be made as paper-free as possible, although he began by stating that there were legal requirements for certain records to be kept in paper form (consent forms, controlled drugs) as are other records such as ECGs, so

this was not yet a truly paper-free hospital. The 'Electronic Medical Record' forms the basis of the system, which provides fast access to a portable system with no lost notes. It allows for decision support and interactive checking of entries. It also produces data for research and management data for accurate costing. The system has been driven by business needs and been developed via a structured demonstration with an interested supplier. Implementation started before patients began to use the hospital and staff had helped with project management allowing problems to be solved early. Patient management crossed departments, allowing an efficient use of time without duplication. The system uses a standard interface which is consistent between departments and is easy to use. Clerking is done with a point and click system, but free-text notes can be used and negative questioning is allowed. Tests can be ordered using bar codes and are automatically routed to the appropriate department. The major lessons that the group had learned were to involve clinicians early and to find a powerful champion from the management and clinicians. Training is vital (junior doctors have two full days), good support from the supplier is critical and everybody concerned should work towards an integrated solution.

Dr M P Severs (Queen Alexandra Hospital, Portsmouth) closed by saying that the overall message about IT was positive but that there were a number of key points. Clinicians should know what they wanted before buying a system, implementation should be gradual with work on the trade-offs with the winners and losers from such change. There should be a concentration on advances, and the interface between the clinicians, patients and managers was critical.

References

- 1 Adams ID, Chan M, Clifford PC, Coke WM, *et al.* Computer-aided diagnosis of abdominal pain. A multi-centre study. *Br Med J* 1986;**293**:800-4.
- 2 Sutton GC. How accurate is computer aided diagnosis? *Lancet* 1989;**II**:905-9.

Partners in care

This conference, jointly organised by the Royal College of Physicians of London and the Patients Association, was held at the Royal College of Physicians on Wednesday 1 March 1995. It was the follow-up to a joint seminar held in December 1994 by the Patients Forum with colleagues from the Medical Royal Colleges to discuss topics relating to the main issues of access, information and audit/accountability. The main concerns of this conference were to examine the effects of the health reforms on the present tripartite relationship between patients/consumers, the health professionals who care for them and the managers who administer the services, and to discuss ways and means of improving services and access to them. Approximately 180 people attended, 30 of whom were doctors.

Access to health and long-term care

Have the health service reforms changed people's access to care?

Rabbi Julia Neuberger (The Patients Association, and Camden and Islington Community Health Services NHS Trust) started by identifying certain key factors which determine the success or otherwise of access to care. One is a flexible attitude towards provision of resources. She cited as an example the limited availability of mental health services within her own London borough, which means that many acutely ill people are being denied beds and long-term care that could be available to them in other parts of the country. Flexibility is also essential in the way services are provided; paediatric home care, for instance, could be offered as an alternative to hospital care. Another key factor is a definition of the boundaries between health care and social care; this problem has always been with us but far too many patients still fall between the cracks. A further key factor is the dissemination of good quality information about available services; this includes dissolving language and cultural barriers, if necessary by employing interpreters and seeing this as a proper use of health service money.

She believed that partnership in care has been improving over a long time but wondered how much of this progress is due to the reforms. She offered, as an example, the improved team-work of health professionals and health managers combining to look after people with learning disabilities. She also believed that the patients' relationship with the health professionals is improving in that patients are being afforded more

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