Leading article

Capturing clinical activity – coming to terms with information

The UK health service reforms^{1,2} of the last three years place great emphasis on accountability. All health care professionals are now expected to account for both the quality and the quantity of the work they undertake. Massive investment in information systems,³ however, has not yielded the required information to allow the monitoring of quantity and quality, and it is now realised that this will not be achieved unless clinicians, who generate the data, have ownership, benefits, and interest in the information systems concerned with collection and analysis. The health service statistics pioneered by Edith Korner⁴ are now widely discredited, for the simple reason that those who generate the data have played no real part in its collection or in validation of the information which results. This, essentially managerial information, is not a byproduct of clinical data, the completeness and validity of which could be ensured by regular feedback to clinicians of information that is of benefit to individual patient management and the clinicians themselves for their own interests and for audit and research. There is thus now a growing enthusiasm for clinical information systems in the UK and Europe,⁵ but if these are to contribute effectively to the quality of clinical care and the management and planning of the health service, the information generated by clinicians must be comparable, exchangeable, and understandable. For this to be achieved, there must be a common language of clinical care, shared and understood by all clinicians. The clinical terms project⁶ is a major NHS initiative that aims to achieve this common language through a comprehensive thesaurus of clinical terms.

The clinical terms project

The clinical terms project is a NHS management executive (NHS ME) funded, profession led project, to expand the existing Read coding system into a full thesaurus of health-care terminology.

With the aid of the Conference Information Group of the conference of joint Royal Colleges (CIG) and the NHS Centre for Coding and Classification (NHS CCC), the profession has been divided into 43 specialty areas, each led by a specialty working group.

Aided by fully funded research registrars, the specialty working groups are now constructing lists of terms and arranging them into clinically logical hierarchies, which will be combined to form the new Read system. Areas of clinical language that do not naturally fall to any one specialty, are either being considered centrally by the CCC's mainly GP staff or by generic groups made up of members from a number of specialty working groups.

The main work of the groups is due to finish by October 1993, by which time, a wider circle of clinicians will have piloted the specialty working group's work. From then until April 1994 (the final delivery date of the project), the CCC will assemble and check the completed Read set, ready for distribution to software developers. The work will not stop there, however. The NHS ME has earmarked more funds for a continuing development programme. This will ensure that the terms always remain abreast of new medical advances and also keep pace with more ambitious use of medical information within the NHS.

Gastroenterology is represented by four of the specialty working groups, embracing upper gastrointestinal tract; lower gastrointestinal tract; liver and biliary system; and pancreas and general surgery.* Each group has its own research worker. There is also an overall gastroenterology working group made up of the four chairmen, a gastroenterology project manager, and a number of representatives from professional bodies (Royal College of Surgeons and the British Society of Gastroenterology, for example). This group coordinates the approach of the four gastroenterology groups and provides some organisational assistance through the project manager.

The clinical terms project hopes to tackle not only procedure and diagnosis coding but advance into much more complex areas such as special investigations, social history, general health status, symptoms, and signs. Since its inception, the project's scope has been extended to cover professions allied to medicine, and nursing terminology, thus expanding the Read set still further.

In addition to being by far the most comprehensive coding system ever devised, Read version 3 (as the product of the clinical terms project will be known) is also a technical breakthrough. Through its file structure, system developers will present users with a relevant set of terms, arranged in a clinically logical manner, while still permitting access to more rarely used terms if required. Extensive use of synonyms, collected as the project progresses, will permit clinicians to use their preferred terminology without any subsequent loss of data accuracy. This ease of use, combined with the additional technical benefits of virtually limitless expansion potential, seamless updates, and smaller more compact files, are designed to fulfil the goal that the NHS ME has set out for the Read codes, that of the only recognised medium for electronic clinical information.

Issues

The extent of this project is shown, not only by the number of people involved (43 specialty working groups and more than 500 clinicians), but also by the volume of terms being generated. The gastroenterology working groups have delivered 1200 acronyms to be coded by the Read centre. Diagnoses, procedures, special investigations, symptoms, signs, and drugs have followed. The method of coding complex terms is an important issue. For example, Crohn's disease is a diagnosis that is well understood, and for the most part definable. It is a condition, however, which may affect any part of the gastrointestinal tract. The diagnosis can therefore be amplified by anatomical attributes to point to the part in the gut which is or are affected. If this is the colon, the code for Crohn's colitis will therefore be a complex of the code for Crohn's disease and the code for colon. What then is the code for Crohn's colitis itself? Should this be an amalgam of all codes, or should there be a separate code? It is even more complex when one considers endoscopic procedures or surgical operations.

The creation and organisation of hierarchies that are acceptable to specialists within the field of gastroenterology, and yet useful to generalists, who may use less specific but nevertheless, meaningful and common terms, is another

difficult issue. There is often more than one way of viewing a particular condition, and without the ability to duplicate terms within a hierarchy, a solution is often less than satisfactory. It is not entirely satisfactory to combine within a thesaurus of terms synonyms that may have subtle differences of meaning to different users. The project is also identifying preferred terms, which will take into account recent advances in research and opinion, but in some cases change long held historical views.

Ulcerative colitis is a diagnosis which illustrates all these issues. It is a common condition to gastroenterologists, both medical and surgical, and to the medical profession as a whole. A generalist may only want to recall the term ulcerative colitis, but to the specialist, the degree of involvement is often of crucial importance. It can be viewed as a form of colitis or perhaps, more commonly, as a form of inflammatory bowel disease. Both headings are commonly used, but are not necessarily specific. For some, idiopathic proctocolitis may be preferred to ulcerative colitis, and to these people this might be the preferred term.

The language is being identified in the clinical terms project but the definition of terms is outwith the scope. This would not be possible within the timescale or the organisation that is being created, but it is clearly an important task for the future. In some areas this has already been done, for example, findings on gastrointestinal endoscopy have been comprehensively reported by a European working group.⁷ In other areas, however, no such standards exist and considerable work is required. An example are the findings on oesophageal manometry where there is no common language and little consensus.

A related problem is identifying normal ranges. Where is the boundary between normal and abnormal on acid secretion studies, pressure studies of the gastrointestinal tract, histological indices of inflammation in the small bowel? If normality cannot be defined then a description must be used, but how will this be interpreted by the generalist?

Important attributes that should be applied to clinical terms if they are to be of value in the capture of clinical activity in an electronic form are measures of severity, function, and outcome but much work is required if comprehensive measures of severity are to be agreed for all gastrointestinal disorders. Classification such as the Savary Miller classification for oesophagitis,⁸ or the Sydney convention for gastritis⁹ are important steps forward, but much work is needed in other areas.

When the capture of clinical activity in electronic form becomes routine, the data to be captured will become increasingly comprehensive, eventually replacing the paper record. The road towards an electronic patient record will be a long one, requiring considerable cultural change as well as considerable research work. The thesaurus of terms being generated by the clinical terms project does not include any attempt to capture the dynamics of care – the relevance of symptoms and findings, the responsibility of care, the setting of goals and planning of treatment schedules, the optimisation of care. This requires a further major project that will be an even greater catalyst to the integration of disciplines, and an inevitable outcome of this process – multidisciplinary records and multidisciplinary working.¹⁰

The clinical terms project is thus the first step along a long road. Gastroenterology is deeply affected, but there needs to be central coordination to ensure that the way forward has the backing of the profession and the support of the professionals. The benefits to clinical care will be enormous: comprehensive information on individual patients to permit better informed decisions; comparable data to permit audit of the quality of care and large databases of accurate, valid, and comprehensive data to permit research. The move towards this is relentless and the change inevitable. The profession must participate.

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*The pancreas group now has taken on responsibility for the topic of general surgery in addition to its gastroenterology topics.

- 1 *Working for patients*. London: HMSO, 1989.
- 2 *Working for patients working paper No 6. Medical audit*. London: HMSO, 1990.
- 3 *Working for patients working paper No 11. Framework for information systems: overview*. London: HMSO, 1990.
- 4 *Steering group on health services information. 1st Report to the Secretary of State*. London: HMSO, 1982.
- 5 Adlassnig KP, Grabner G, Bengtsson S, Hansen R, eds. *Medical informatics Europe 1991 Proceedings, Vienna, Austria*. Berlin: Springer-Verlag, 1991.
- 6 Buckland R. The language of health. *BMJ* 1993; 306: 287–8.
- 7 Maratka Z, Colin-Jones DG. *Terminology, definitions and diagnostic criteria in digestive endoscopy*. Bad Homburg: Normed Verlag, 1989.
- 8 Savary M, Miller G. *The oesophagus. Handbook and atlas of endoscopy*. Solothurn: Gassman, 1988.
- 9 Gastroenterologists in Sydney: histology in *Helicobacter*. *Lancet* 1990; 336: 779–80.
- 10 Williams JG, Roberts R, Rigby MJ. Integrated patient records: another move towards quality for patients? *Quality in Health Care* 1993; 2: 73–4.