A new approach to patient indexing

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SUMMARY A computer based rheumatology patient index is described. Patients are indexed according to essential clinical and laboratory data without reference to Procrustean diagnostic labels. The stored information can be searched for a wide range of practical and scientific purposes. The software was devised in the windows environment for the Apricot Xen for maximum speed and intelligibility.

The philosophy behind this index has been outlined in a viewpoint article in the *Annals of the Rheumatic Diseases*.¹ The basic assumption in designing the index was that diagnostic categories in current use are less useful than the clinical and laboratory evidence of disease processes from which they are derived. This applies equally to clinical practice and scientific enquiry.

The index was set up to establish whether a core of information could be gathered on new outpatient attenders which required no more effort than a traditional 'diagnostic' index, but which could provide a more reliable and versatile database.

Detailed description

SOFTWARE

A software package was devised by KT using the computer language 'C', the windows environment, and Apricot Xen hardware. The software was designed solely for the index. On starting up the index is entered immediately, avoiding time consuming and confusing menu options. The data files created, however, can be used for other purposes if required.

The windows environment is pleasant to the eye, allows handling with a mouse or with the keyboard, and the overlay system allows the user to 'keep in touch' with general information about the file being created. The software consists of three main program units; for entering data, for searching, and for printing out.

DATA COLLECTION

Printed sheets carrying an inventory of clinical and

laboratory features and associated alpha-numeric codes are put loose into the case notes of all new outpatient attenders. (Previously discharged patients reattending for new problems are treated as new.) Medical staff ring the chosen codes, and the sheets are collected together. Once a month the data are entered on the computer, every sheet having been checked by a single doctor (JCWE).

PRINTED SHEETS

The printed sheet is reproduced in Fig. 1. The inventory is divided into the following sections: (i) identification, (ii) site(s) of rheumatic problem(s), (iii) type of rheumatic problem, (iv) common associations with rheumatic illness and other common disorders, (v) laboratory information, treatment, and name of consultant. Items are allocated codes. The rather cryptic nature of these codes relates to complex rules designed to prevent wasteful searches, which will not be described in detail. A space is also provided for 'rarities' which may consist of up to 50 characters. There is no other restriction on the entry in this category.

Entries follow rules designed for speed. All patients have section (i) filled in by clinic staff. The site of rheumatic problem must be entered, unless there is no rheumatic problem or pain is of 'dubious soft tissue origin (A00)'. For common problems, such as shoulder, neck, or lumbar pain no further details are obligatory, but synovitis, cartilage loss, osteophytes, or nerve entrapment can be added if desired. Certain sites are linked to a typical local lesion, as for elbow epicondylitis and sacroiliitis. Where several joints are affected by a particular process (polyarticular) this must be specified in category (iii). Category (iii) provides information on rheumatic disease according to the type of disease process.

Accepted for publication 16 May 1987.

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PATIENT INDEX FORM

SURNAME _____		HOSPITAL NO. _____	
SEX	M / F	YEAR OF BIRTH	19 ____

SITE			
A0 Normal JOINTS A1 Polyarticular A2 Shoulder A4 Elbow (articular) A5 Wrist A6 Hand A7 Hip A8 Knee	A00 Doubtful : soft tissue lesion A9 Ankle B0 Foot B00 Toes B7 Sacroiliac : mech B70 Sacroiliitis B5 ACJ/SCJ B6 TMJ	SPINE B1 Neck B3 Thoracic : +0=Disc B4 Lumbar SOFT TISSUE B01 Plantar/heel A3 Epicondyle M0 Muscle	B9 Tendon B8 Trochanter

MUSCULOSKELETAL DISEASE			
JOINTS C0 Peripheral joint pain or swelling : cause uncertain C1 Synovitis, immunological (i.e. no other cause) +0 Non-erosive +1 Erosive +2 Nodules +4 Post infective +5 Asymmetric +6 Mutilans C2 Cartilage loss : query cause G0 Hyperuricaemia X1 Calcium crystal deposition	C3 Cartilage loss : cause known G1 Gout I1 Joint infection	K Childhood onset +3 Palindromic +7 DIP C4 Osteophytes/Heberden's Nodes	
RARITIES : Specify _____			
SPINE C5 Spondylitis MUSCLE M1 Polymyalgia M2 Myositis M3 Myopathy	BONE X0 Bone disorder X2 Osteoporosis X3 Osteonecrosis X4 Dysplasia X5 Paget's	VARIOUS Y Trauma : all types I2 TB D0 Amyloid D2 Scleroderma/PSS D3 Sarcoid D4 Algodystrophy C7 Musculoskeletal tumour Y1 Hypermobility	

ASSOCIATIONS		
SICCRA RELATED CLUSTER J0 Sicca Sx J2 Lip biopsy +ve U3 Nephritis N2 Cerebritis S3 Skin vasculopathy S4 Discoid LE S5 Raynaud's S6 Photosensitivity/butterfly rash H2 Neutropenia H3 Lymphopenia H4 Thrombocytopenia V3 Carditis L5 Serositis L3 Pulmonary fibrosis	SPONDYLITIS RELATED CLUSTER U0 Urethritis/Balanitis N8 Conjunctivitis N9 Uveitis E2 Crohn's/U.C. E3 Dysentery E4 Mouth ulcers S1 Psoriasis S2 Nail dystrophy	MISCELLANEOUS N1 Neuropathy N10 Entrapment P0 Psychological component V1 Necr. Arteritis V4 G.C. Arteritis W1 Thyroid W2 Diabetes Q Allergy

TESTS / TREATMENT / CONSULTANT				
Rose Waler + -	ANA + -	DNA + -	ENA + -	B27 + -
T1 Steroids	T2 Immunosupp.	T3 Surgery	T9 Drug reaction	
MC MLS MES DAI JCWE AE BCZ			FORM COMPLETE ? _____ (tick here)	

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Fig. 1 Inventory of common problems for indexing of patients. Unusual problems are recorded specifically under 'Rarities'.

Other categories are filled in if appropriate information is available and of interest.

SEARCHING PROCEDURE

Any single code or combinations of up to three codes can be searched for. Data on patients carrying those codes are printed out in monthly sets.

The index has proved practical. Filling in codes in the clinic takes about 10 seconds. Vetting and entering data on the computer takes an hour each month. Where clinicians had initial difficulty in deciding how to code patients they were encouraged to write problems out manually, and these were discussed before being entered onto the computer.

The index has been running for nine months, and 800 patients have been indexed. There is a lag in indexing in some cases because the doctor can hold the printed sheet back until the second, or occasionally the third, visit so that important laboratory data can be entered. The completion rate is checked against the clinic manager's monthly statistics.

It is possible to establish how many patients with rheumatic problems and psoriasis are seen in a given period. The printout gives a breakdown of how many have spondylitis, synovitis, erosions, etc. A single consultant can see how many patients with shoulder pain he has seen, to assess the impact of introducing a policy of early appointments for such patients, or entry into a treatment study.

In addition to monthly new patient files, an old patient file has been set up. This takes patients of continuing interest, rather than all attenders. A clinician interested in azathioprine can index all his cases on the drug by adding 'AZA' to the other codes and search under 'AZA'. A few spurious records may appear with this type of search but are easily weeded out.

As can be seen the information recorded and

searched for is highly flexible, but common problems are highlighted by the structured coding system.

Discussion

The point of departure of this index lies in the idea that clinical and laboratory data should be stored without reference to a diagnostic label. It is far from clear that all rheumatologists have the same concept of the processes represented by terms such as osteoarthritis and rheumatoid arthritis. If we are to explore the heterogeneity and overlap of different elements of these processes then it is inappropriate to store data under such headings.

Users of this index who wish to collect patients by current diagnostic criteria have no difficulty in doing so. Most criteria are recorded in the inventory. A screening index of this sort cannot be expected to provide completely up to date and reliable information, whatever the coding system used, and all searches must be checked by reference to the notes or by seeing the patients.

Any index is a compromise between speed of use and thoroughness of documentation. The suggested index is only marginally more complex than previous indexes used in our combined departments. Because the data have not been reduced to a single diagnosis, however, it allows rapid searching for information in a wide range of contexts and combinations. It is not perfect, but we feel it moves in the right direction.

We would like to thank the special trustees of the Middlesex Hospital for financial support for this work.

Reference

- 1 Edwards J C W. Diagnostic categories in rheumatology. *Ann Rheum Dis* 1987; **46**: 259-61.