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.

PATIENT INDEX FORM

SURNAME _____   HOSPITAL NO. _____

SEX   **M / F**   YEAR OF BIRTH   19___

SITE

A0 Normal		**A00** Doubtful : soft tissue lesion		
JOINTS			SPINE	
A1 Polyarticular	**A9** Ankle		**B1** Neck	
A2 Shoulder	**B0** Foot		**B3** Thoracic	**+0**=Disc
A4 Elbow (articular)	**B00** Toes		**B4** Lumbar	
A5 Wrist	**B7** Sacroiliac : mech		SOFT TISSUE	
A6 Hand	**B70** Sacroiliitis		**B01** Plantar/heel	
A7 Hip	**B5** ACJ/SCJ		**A3** Epicondyle **B9** Tendon	
A8 Knee	**B6** TMJ		**M0** Muscle **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   **+3** Palindromic
  +4 Post infective   **+5** Assymetric   **+6** Mutilans   **+7** DIP
C2 Cartilage loss : query cause   **C3** Cartilage loss : cause known   **C4** Osteophytes/Heberden's Nodes
G0 Hyperuricaemia   **G1** Gout
X1 Calcium crystal deposition   **I1** Joint infection

K Childhood onset

RARITIES : *Specify* _____

SPINE	BONE		VARIOUS	
C5 Spondylitis	**X0** Bone disorder		**Y** Trauma : all types	
	X2 Osteoporosis		**I2** TB	
MUSCLE	**X3** Osteonecrosis		**D0** Amyloid	
M1 Polymyalgia	**X4** Dysplasia		**D2** Scleroderma/PSS	
M2 Myositis	**X5** Paget's		**D3** Sarcoid	
M3 Myopathy			**D4** Algodystrophy	
			C7 Musculoskeletal tumour	
			Y1 Hypermobility	

ASSOCIATIONS

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

TESTS / TREATMENT / CONSULTANT

Rose Waaler + -   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 department. Because the data have not been reduced to a 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.

Reference

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