Middle Articles

Computer-assisted Follow-up Register for the North-east of Scotland

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Summary: An automated follow-up register for the detection of iatrogenic thyroid disease has been established as a joint venture between the general practitioners in the north-east of Scotland and the thyroid clinic of Aberdeen General Hospitals.

The data-processing operations in the system are handled by an International Computers Limited 4/50 computer. Patients are followed up at predetermined intervals and the system has been designed to process, screen, and store clinical and biochemical follow-up data and report results to the patients, general practitioners, and the hospital records department.

Introduction

Retrospective studies (Crooks, 1965; Hedley *et al.*, 1970) which have evaluated the problem of iatrogenic thyroid disease have shown a high level of undetected morbidity. There is therefore an urgent need for a practical and economic system which will continue to follow-up "at risk" patients at predetermined intervals and on a prospective basis from the time of treatment.

A screening procedure for the detection of late onset hypothyroidism after radioiodine therapy was originally devised and based on a mechanical data-processing system (Philp *et al.*, 1968). This system has now been extended to cover different types of treatment for thyroid disease, and the data-processing operations in the follow-up registry have been developed on the Aberdeen University ICL System 4/50 computer (Hedley *et al.*, 1969).

The Problem

This work was originally stimulated by the need to detect hypothyroidism and recurrent hyperthyroidism arising as long-term complications of destructive therapy (radioiodine and subtotal thyroidectomy) for thyrotoxicosis. In addition, the system covers the long-term follow-up of patients in remission after antithyroid drug therapy and all patients re-

ceiving lifelong thyroxine replacement therapy for primary, secondary, or iatrogenic hypothyroidism.

The full extent of the needs of these patients is now appreciated. For example, all patients treated with radioiodine for thyrotoxicosis are at risk of developing hypothyroidism, and patients treated surgically carry the double risk of either hypothyroidism or recurrent hyperthyroidism. The use of antithyroid drugs alone offers a reversible form of treatment and leaves the gland intact, but at present about half the patients achieving remission in this way are at risk of recurrent hyperthyroidism. Finally, there is now convincing evidence that the initial prescription of lifelong replacement therapy does not provide infallible protection against hypothyroidism in the future. For several reasons (often unknown to the general practitioner) tablets may be stopped or reduced by the patient. Unfortunately the actual point in time at which these complications will occur is unpredictable for the individual patient. This has led to an unacceptably high incidence of undetected morbidity.

Difficulties of Long-term Follow-up

The responsibility for this type of follow-up has lain in the past either with the patient's general practitioner or with the hospital outpatient department service. The reasons why follow-up often fails are numerous.

General practitioners have no access to appropriate laboratory and data-processing facilities. Hospital resources are fully committed and the division of responsibility for follow-up between consultant and general practitioner is not clearly defined. If the hospital takes on the obligation to follow up all the patients it is encroaching on the responsibility of the general practitioner. In addition, this would result in a cumulative clinic load, with all previously treated patients who require follow-up being added to the new referrals each year. The hospital outpatient service would be faced with saturation of its resources and inevitable reduction of facilities available to other patients.

Doctors move and retire, patients migrate, and regular attendance at outpatient clinics is disliked by many patients and is often inconvenient. When a medical centre like Aberdeen serves a thinly populated area such as the north-east of Scotland, the difficulty, inconvenience, and expense associated with travelling to central clinics reduces the likelihood that successful contact will be maintained with patients over a long period of time.

Finally, the onset of complications, particularly hypothyroidism, is often insidious and dissociated in time from the original treatment.

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All these factors have contributed to the failure of communications between hospital, general practitioners, and patients.

The system which has been developed to overcome these difficulties is based on acceptance of the principle that the responsibility for primary patient care lies with the general practitioner and that it is the responsibility of the hospital to make available to him the facilities which he cannot provide for himself to perform this function. The new system is therefore intentionally based on domiciliary care and supported by automated data-processing facilities in a central follow-up registry.

New System

Follow-up of thyroid patients in the post-treatment situation involves making a decision at predetermined intervals on whether a patient is euthyroid or not. The problems associated with this diagnostic situation have been studied by Billewicz *et al.* (1969), and it has been shown that a standard clinical examination and at least one laboratory test of thyroid function provides effective discrimination between those patients who are euthyroid and those who may be hypothyroid and require further investigation.

Follow-up Procedure

The patients whose aftercare is supervised by the system are those treated at a joint medical and surgical thyroid clinic and the corresponding general medical and surgical wards at the Aberdeen Royal Infirmary.

Four standard forms are used by doctors in hospital and general practice to communicate with the registry (Table 1).

TABLE 1.

Basic Documents	Completed By:
F.U.R.* 1, Initial registration form	Hospital doctor
F.U.R. 2, Final registration form	Hospital doctor
F.U.R. 3, Follow-up form	General practitioner
F.U.R. 4, Hospital record of follow-up results ..	Medical records department

*F.U.R. = Follow-up record.

Forms 2 and 3 are destroyed after the information they carry has been transferred to punched cards.

At the time of destructive therapy (Fig. 1) the patient who has been placed at risk is identified by an initial registration form (F.U.R. 1), which is filed in the registry. This manual

FIG. 1.—Flow diagram of automated follow-up register.

file may be scanned at six-monthly or yearly intervals and provides a check against the possibility that the need for follow-up has been overlooked.

When the patient has been stabilized at the outpatient clinic and is euthyroid, with or without thyroxine replacement therapy, final registration is carried out by the hospital doctor using the second form (F.U.R. 2). This activates the registry procedure for *all* patients who require long-term follow-up. The identification data and details of treatment are transferred to machine cards and a personal cumulative record is created on the computer file for each patient. At this point an approach is made to the general practitioner, who then decides whether or not to use the register in the surveillance of this particular patient.

When follow-up is due the computer sends letters to the patients, who are asked to attend their general practitioners for a check-up. Each general practitioner simultaneously receives a follow-up kit, which contains: a letter indicating that follow-up is due; the follow-up form (F.U.R. 3), which is combined with a clinical diagnostic index for hypothyroidism (Billewicz *et al.*, 1969); a syringe capable of conversion to a sample bottle for collection of blood on which the serum protein-bound iodine will be measured; and a prepaid package in which to return the clinical information and blood sample to the registry.

When the laboratory analysis has been completed the clinical and biochemical data are transferred to machine cards by the registry secretary. The computer applies predetermined weightings to the clinical diagnostic index and calculates a diagnostic score. Normal and abnormal clinical and biochemical results are separated and the patient's file is updated.

Normal results are reported direct to the general practitioner and the follow-up continues automatically. Abnormal results are scanned by the hospital doctor, who has the option to recall the patient to the outpatient clinic or allow the patient's follow-up to continue through the register. Patients recalled to the clinic are investigated and, if necessary, treated and restabilized. Reregistration is then carried out by the hospital doctor, again using the form F.U.R. 2.

The clerical procedures in the registry are carried out by one medical secretary, and medical supervision of follow-up data by a hospital doctor occupies about two hours a month. The system reports results direct to the general practitioner and provides him with a prepaid letter to inform his patient. The follow-up examination takes only 10 minutes per patient each year, and the method of reporting obviates the need for a return visit.

Computer Output

The programme is run at monthly intervals, when all lists and labels prepared by the update programme are output to the line printer (Table II). These items facilitate communi-

TABLE II.

1. Lists of Patients Overdue for Follow-up (Six Months Overdue)
2. Lists of Patients Overdue for Follow-up (Four Months Overdue)
3. Lists of Patients Overdue for Follow-up (Two Months Overdue)
4. Lists of Patients Due for Follow-up
5. Coded Address Labels for Letters to General Practitioner and Patient Requesting Follow-up
6. Headings for Follow-up Form F.U.R. 3
7. Lists of Patients Overdue for Reregistration from Outpatient Clinic
8. Lists of Patients with Details of Abnormal Results
9. Lists of Patients with Normal Results
10. Report Label of Follow-up Results for Hospital Medical Records
11. Coded Address Labels for Letters to General Practitioner and Patient Reporting Normal and Abnormal Results

ciation between registry, general practitioner, and hospital with minimum involvement of secretarial and medical personnel. The registry communicates with doctors and patients by

means of carefully worded preprinted letters. The task of the secretary is simply to pair coded address labels to letters and forms.

Implications of System

This system ensures continuity of care, automates all the stages which do not require a decision by a doctor, and guarantees contact between general practitioner, hospital laboratory, and patient whenever it is required. The patient's records in hospital and general practice are updated with follow-up results, and deaths occurring out of hospital are routinely recorded. In this way patients whose follow-up is incomplete are quickly identified and the reasons are ascertained. Most important of all, the new link established by the follow-up registry raises the possibility of a truly collaborative relationship between hospital and general practice.

It has been suggested that patients should be investigated only when they specifically request the help of their own doctor. This particular anxiety was caused by the possibility of large-scale screening in patients who had not previously been under the care of their own doctor for the condition in question. The present situation is entirely different, and the onus is on doctors to make certain that the long-term effects of treatment are adequately controlled.

There may also be concern on the part of the profession that this type of innovation will disrupt the personal relationship between doctor and patient by the introduction of automated methods in the field of patient management after discharge from hospital clinics. This, of course, is not the case, as the follow-up scheme has been designed to ensure personal contact between patient and doctor when it is necessary—a point that certainly cannot be made in respect of care which is left for the patient to initiate.

There is an unfortunate misunderstanding on the part of some patients and doctors regarding the role of computer facilities in medical care. The object is not to replace the physician or usurp the confidence patients experience from contact with their own family doctor. The aim is to free the doctor so that such contacts are more timely and meaningful.

Such is the scope of modern therapeutics that a vast amount of iatrogenic morbidity is missed, and our efficiency in providing certain types of medical treatment has far outstripped our ability to provide effective aftercare. The rapid advance of medical and surgical practices has created an urgent need for an effective and reliable system of communications in medicine. It is a service and protection which we owe to patients. The development of this system will greatly increase the opportunities for general practitioners to provide comprehensive medical care.

This exercise in preventive medicine depends on the fullest co-operation between hospital doctor and general practitioner which in itself is a powerful argument for its acceptance and development.

Future Development

At the present time 400 patients are on the register, and registration data are being prepared for a further 400. It is estimated that by the end of 1970 1,000 patients will be on the register and new patients from the north-east of Scotland will be added at the rate of over 100 a year. (Fig. 2.)

The programmes have been written in such a way that patients in other disease groups can be followed up by using the existing link between the registry and general practice. The programmes are also capable of serving different hospitals and different departments within each hospital. Development of the follow-up system, based on domiciliary care and central facilities for data processing, will enable the general practitioner to control the management of several groups

FIG. 2.—Area covered by north-east Scotland automated follow-up register.

of patients within his own practice who require short-term or long-term surveillance, with periodic investigations or other routine procedures. These could include immunizations, cervical smears, and any laboratory tests on blood and urine.

The system could be extended to other regions, where hospitals and general practitioners could be served by, and communicate with, one central data-processing facility. The feasibility of establishing such a national follow-up register in Scotland for patients treated for thyrotoxicosis is at present under investigation.

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