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# A simple computerised Tuberculosis register with data collection in the field (suitable for a developing country)

BY

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An earlier communication<sup>1</sup> described the organisation of the tuberculosis service in Matabeleland, and how the simple card index register enables us to keep track of patients and control their treatment. This paper discusses the second major role of a tuberculosis register, that is as a repository of clinical and epidemiological information from which material can be extracted for statistical analysis; and how we have been able to introduce this second function at little extra cost and within our existing slender manpower resources.

There is sufficient tuberculosis in the province for any organised assault upon it to produce a demonstrable effect, and that the inception of

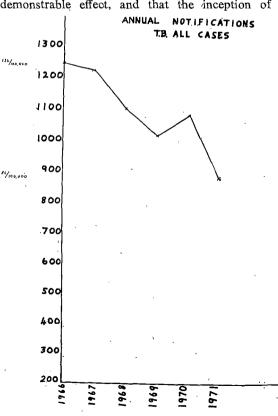
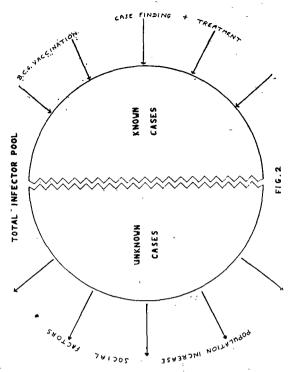


FIG. 1



the service was followed by a steady reduction in the number of cases being notified was only to be expected. This trend is shown in Fig. 1; but that no facile, and posibly erroneous, conclusion should be drawn from this is illustrated in Fig. 2. This shows a diagram of the total infector pool divided into its two components. known part consists of all known cases of tuberculosis. The unknown part consists of people who, although sick, do not seek medical advice. Typical reasons for this are a fatalistic acceptance of ill-health, fear of losing jobs, a belief in traditional medicine, lack of funds to pay for available transport. The unknown part of the pool also contains people who, although suffering from the disease, are not yet aware that they are siok.

A large part of our rural population live in relatively densely populated tribal areas or on scattered farms and ranches. Many of these areas are remote and poorly served with both medical and transport services.

With 'the increasing acceptance of Western medicine by the indigenous people we hope that we know, and are treating, the greater part of our tuberculosis, but we do not know for sure whether or not this hope is justified, or to what extent. The two parts of the infector pool are shown in the diagram as being equal, but it would be a curious coincidence if this were in fact so. In dealing with a social disease it is reasonable to assume that if there is no improvement in

social conditions the amount of the disease will increase at least pari passu with the increase in population.

It may, of course, increase even faster if the population increase leads to an exacerbation of those social conditions such as overcrowding and malnutrition which predispose to the disease. It follows that, while our attack may be reducing the known amount of tuberculosis, the unknown amount may be tending steadily to increase. This would be particularly likely, for instance, if our mass B.C.G. vaccination programme was not being effective. The relative size of the two parts, and their rates of increase and decrease, are thus vital factors in determining what is happening to the infector pool as a whole.

Since some of it is unknown we can clearly never know the actual size of the infector pool. This does not matter; what we do need to know is whether it is getting bigger or smaller, and a valuable guide to this is the average age at which primary infection is occurring. The greater the amount of the disease present in a population the earlier the age at which infection will occur. If the average age of patients with primary infection is increasing then the total amount of tuberculosis is decreasing. It is possible that the proportions of the various degrees of positivity of the tuberculin test may provide a similar indication.

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There are many other questions to which we do not, as yet, know the answers; only a few examples will be given. What is the incidence and severity of tuberculosis in patients who have had a previous B.C.G. vaccination? In other words, how effective are our mass vaccination campaigns in our field conditions? How effective are our drug regimes? What is the incidence of drug resistance (both primary and acquired) to the various drugs in use? What is our relapse rate and can it be related to any specific factors?

A vast fund of information which could give us the answer to these, and other, questions (if it could be analysed) was already recorded in the clinical records of patients receiving treatment or under surveillance at the 17 hospitals in the province which act as tuberculosis review centres, but we have had no effective method of extracting it for analysis. To answer just one particular question would mean employing staff to visit every hospital, scrutinise every T.B. record, extract the information relative to the investigation, consolidate it and analyse it either manually, or by coding and the use of punch cards. This is a laborious process and one which would have to be repeated on every occasion that a statistical analysis was required. It is an impossible undertaking in an under-developed country such as Rhodesia where all resources, and especially those of manpower, are strained to the utmost. We needed a system which would enable the information to be concentrated, and readily extracted and analysed when required.

Computers are highly sophisticated pieces of equipment which are frequently held to be the prerogative of the highly developed countries. To contemplate the use of a computer in an under-developed country to achieve the desirable goal set out above might be held to be trying to run before we could walk, and such opinions were, in fact, expressed. However, I believe that the more severe the labour shortage the more important it is to use labour-saving devices. If science produces a tool which will be useful to us, and it is available, then it behoves us to use it. The computer is such a tool.

Having decided to make use of a computer the first question to be decided was, "how to make use of it?" The storage and retrieval of medical records can achieve all levels of complexity, but it was clear that any system which we adopted would have to be limited in scope, and simple to operate at the level of data collection in the field, bearing in mind that the bulk of the data would have to be supplied by Health Asisstants or by over-worked doctors or nurses in government and Mission hospitals.

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In introducing a new procedure of this nature it is of paramount importance that it be acceptable to those who will have to use it. It must be primarily a medical tool and not just an exercise in computer expertise. Failure to appreciate this fact is to court disaster, as Ofit and Woodroffe report from University College Hospital.<sup>2</sup>

With this in mind from the beginning a number of fundamental concepts were formulated. We must not be too ambitious in the amount of data we wanted to collect, it should be limited to what could be collected on a single form. It was felt that to have more than one form would immediately cause difficulty and confusion. The new system must oreate as little extra work as possible

as we should have no extra staff to operate it. It was decided, therefore, that completion of the data collection forms should involve as little writing as posible; that the information required would be printed on the forms in such a way that in most cases the addition of a date or a tick in an appropriate box would be all that was required. Since such material as names and addresses would have to be entered on the initial form it was decided that this would take the place of the standard form of notification of infectious diseases in so far as tuberculosis was concerned, thus avoiding unnecessary duplication.

A list of useful data for statistical purposes was then compiled, and a form was eventually de....

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signed which accommodated as much of this list as possible within the compass of a single foolscap sheet. With the advent of decimalisation this was transposed in the printing to the decimal size DIN A4. Certain items of the original list had to be omitted because it was found not possible to fit them in. So, after a somewhat difficult delivery, was born our original T.B. Notification and Report Form (Fig. 3).

Having produced the means whereby simple basic data might be collected at the periphery for central storage and processing, the next step was to sell the idea to all concerned. This, in the event, proved easier than had been anticipated. Every doctor in the province likely to be involved indicated his or her willingness to co-operate, though some expressed misgivings about the extra work involved or about their ability to have the forms completed properly. At the regular T.B. reviews the idea of a computerised register was sown and fostered over a considerable period of time by discussions and the reporting of developments. Detailed instructions for the completion of the form, box by box, were prepared and circulated with the initial issue of books of forms. Health Assistants spent one full afternoon of their annual conference being instructed in the forms and their use, and at ensuing reviews forms were completed by myself as illustration.

This careful preparation of the ground to ensure user acceptability brought results which far exceeded even my hopeful expectations, and confounded the pessimists who had predicted that the whole exercise would prove far too complicated for our staff to cope with. It was explained to all concerned that forms incorrectly or incompletely filled in would be returned and that they must not be upset or resentful about this. We were all learning as we went along and this was the best way to ensure familiarity with forms and accuracy in their compilation in the shortest possible time. In the event a far smaller number of forms had to be returned than had been anticipated. In many cases information omitted from a form would be pointed out at the next review and a supplementary form including the missing data would be completed at that time.

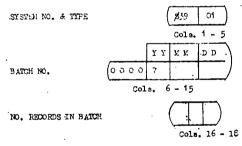
A simple coding sheet (Fig. 4) had been prepared for us by a member of the staff of the computer bureau and the T.B. Clerk began to code the information from the data collection forms as they arrived in the office. As data collection started before the computer bureau could begin programming, all this paper had to be held in the provincial T.B. office until the bureau could accept it for punching. This was in some ways not a bad thing as during this period we were able to make corrections to the forms before they were

submitted for processing. Most of these corrections were necessitated by our unfamiliarity with coding or with the programming requirements, but some resulted from alterations to the programming after coding had been completed. Correcting the material beforehand involved the individual checking of the stock-pile of thousands of forms on several ocasions. It must have enormously reduced the number of pages of error listings printed by the computer after processing had started and, though it may have increased the total amount of work, it did serve to spread the load. Also, and very valuably, it provided the bureau with a considerable bulk of reasonably accurate material which could be used for testing the various programmes.

Throughout the ensuing 12 months numerous lengthy meetings were held with an officer of the computer bureau. The object of these meetings was to determine the best way in which the material should be held on the computer in the light of the probable demands upon it. The design of the various print-outs which we should be requiring (review sheets, annual report statistics, etc.) was agreed. We learned what the computer could do easily, what could be done only with difficulty, and what it could not do. Not least, we learned how to avoid errors and received much help with the corrections.

#### T.B. STATISTICS

#### BATCH CONTROL VOUCHER



#### NOTES

- Use current date for Batch No. but do 1. not oreate more than one batch with the same date.
- All input documents must be batched and submitted in a logical sequence.
- If both sides of an input document are coded, treat as TWO records; otherwise treat as ONE record.

OTAL	NO.	DOCUMENTS IN BATCH		
		SIGNED	•••••	

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### A COMPUTERISED T.B. REGISTER

THE CENTRAL AFRICAN JOURNAL OF MEDICINE

00001 ANNUAL ANALYSIS OF TUSERCULUSIS NOTIFICATIONS IN MAIABELELAND IN 1971 PAGE 1 PISTRICT BIGCHEAIG (10-20) (20-30) (30-40) (40-50) (50-60) (60-70) HHERE CONTRACTED ON BELT BRIDGE EUR YFAVOFIUR 20 NON PULYONARY 3 2 TOTAL 1 PULMONARY PUS PULMONARY NEG DINGA NON PULMONARY TOTAL BULAWAYD HUN PULHONARY PUB BON YRAYCFUNG NON PULMONARY 10 9 12 12 +3 1± .37 9 38 17 RSSEXVALE PULMONARY PUS PULMONARY NES 1 YPAYCHILG MON TOTAL z FILABUST PULTONARY PUB NON PULMONARY FIG. 8 TOTAL TARK SURVEY OF T.B. NOTIFICATIONS IN MATABELELAND AS AT 11 DECEMBER 1971 (PULKCNARY) (NON PULMON) (ALL CASES ) **HACE** YKAR NOTIFIED BYO <u>01</u>H 107 BYO OTH <u> 101</u> TOT AFRIC AN 1962 1963 1964 1965 1967 1968 1969 1970 1971 115 206 207 214 232 308 672 844 733 674 695 470 1057 1050 940 688 1042 999 880 766 634 545 23 24 22 24 25 35 170 155 147 112 139 75 193 179 169 136 164 208 230 229 238 257 343 927 778 COLOURSD 1962 1963 1964 1965 1966 1967 1969 1970 AST ATTO 1962 1963 1964 1965 1966 1967 1968 1969 1970

1962 1963 1964 1965 1966 1967 1968 1970

EUROPEAN

FIG. 9

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In view of the large number of people involved in the process of data collection the possibility of human error assumes major proportions. It was our wish, therefore, that the computer would monitor our activities and draw attention to our errors and omissions. This has been done by linking various items of data either to other items or to specific dates. In only a few cases, however, will an entire record be rejected as invalid. In general, the computer will accept as much valid data as possible and reject only those fields within a record which are invalid or incomplete. Attention is drawn to incorrect material by means of error listing print-out for each batch of documents processed, and to incomplete records by means of a print-out of "missing details" (Fig. 5) concurrently with each hospital review sheet.

The various items of data are listed at the top of the print out and are each provided with a code number. These code numbers are arranged horizontally across the page while the patients' names are listed vertically down the left-hand side of the pages. Asterisks opposite the names under various numbers show the missing details required to bring each patient's record up to date. A few examples will serve to show the sort of linkages with which the system has been programmed in order to achieve this. A sputum culture result must be recorded for every month in which a sputum slide has been recorded, and each positive culture must have a corresponding sensitivity result. If only a slide result is available the culture result must be recorded fictitiously as "contaminated". If this is not done the computer will continue to ask for a culture result until 12 months have elapsed. Reports of cultures and sensitivities will not be accepted if no slide result for the corresponding month has been recorded.

A change of treatment must show a reason for the change and the new treatment regime, and if this is due to drug reaction or patient intolerance the drug or drugs implicated must be shown also. A sputum positive in-patient cannot become an out-patient without evidence of previous sputum conversion. Information regarding contacts will be asked for if the information has not been recorded by the time treatment as an out-patient has been completed, and so on.

We discovered as a result of these discussions that there were various ways in which the computer could help us by way of a bonus, as it were, apart from its primary function. For example, the review sheets list all the patients who fall within the aegis of each hospital, arranged in numerical order within each of the four groups.

In-patients, Out-patients, Surveillance, Absconder/ Defaulter. They provide name, age, sex, diagnosis, the date when the last change in status was notified, columns for the current status and for the various possible disposal instructions. Instructions are recorded by making a circle round a printed dot in the appropriate column. Review sheets were introduced so that register cards could remain in the provincial T.B. office and not accompany the doctor to the various hospitals. This automatic printing is not merely a tremendous saving of typist's time, but the computer also prints an asterisk against the name of every patient who is shown as having been in hospital for more than six months, or who have been receiving continuous treatment for more than two years, or who has defaulted for more than six months. To have ones attention drawn to such cases visually is of considerable value at a busy clinic when one is pressed for time and such things are easily overlooked. Furthermore, one copy of the review sheet is sent to the hospital in advance so that the Health Assistant has an opportunity to investigate and prepare a report on such cases prior to the doctor's visit.

The Tuberculosis and Report forms are completed in duplicate on admission, and whenever additional clinical information comes to hand or there is a change in the patient's statussuch as from In-patient to Out-patient. original copies are sent to the Provincial tuberculosis office and the duplicate remains in the patient's hospital record. The discharge form which comes back to the hospital has the patient's register number on it, and this is entered in the space provided on the T.B. Notification & Report form, together with the suffix "O1". The first digit represents the province and is followed by the register number (five digits). The check letter is a safeguard against accidental transposition, or mis-reading by punch operators, of badly written numbers or letters. The suffix is the folio number of the particular clinical record being stored and each subsequent form will bear the same register number with the folio suffixes rising by successive integers. This permits a total of 99 "pages" in the patient's record — which we hope will be sufficient even for a patient with multiple relapses.

When a T.B. Notification & Report form is received in the T.B. office the information thereon is transcribed on to Coding Sheets. Two copies are made, the duplicate being filed with its data collection sheet in numerical order. The originals are batched and sent to the computer bureau. After processing and when the information has been transferred to the Master File on the computer, the originals are returned to the T.B. office

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with the error-listing print-out. After checking the errors and making corrections where necessary the originals are destroyed. The use of the computer to monitor the material makes it unnecessary to keep copies of all folios, but we always have the most recent folio for every patient on file and can thus ensure that folio numbers are neither omitted nor duplicated. Should this happen the offending document can be returned to the submitting hospital for correction.

In order to reduce the risk of documents going astray, and to assist the punch operators, they are sent to the computer bureau once a week in batches. Each batch has a cover sheet (Fig. 7) bearing a serial number and the total number of both documents and records in the batch. Each coding sheet, or "document" in this context, may bear one or two "records", each representing the format of a punch card. For the serial number we use the year, the month, and the number of batches sent in during the month. e.g. the fifth batch sent in during September, 1972 would bear the number 720905.

Apart from the validation and up-dating error listings for which corrections are required, and which are produced weekly for each group of batches processed, the following print-outs are produced routinely.

- 1. The various tables of annual statistics which have previously been compiled manually (and laboriously) (Fig. 8 and 9).
- 2. The review Sheets (Fig. 6) for the bimonthly reviews at the various hospitals. These were previously typed from the card index register.
- 3. A list of "missing details" (Fig. 5) needed to bring up to date the records of the patients at each hospital. This is produced in conjunction with the review sheets.
- 4. A complete case record print-out of every case that is denotified.
- 5. A complete case record print-out (Fig. 10) of any case on request. Such a request is made by completing an "interrogate" form and attaching it to the next batch of documents to be processed.

Extremely useful though these print-outs are, they are, in a sense, by-products of the main function of the system which is simply to collect and store clinical data in easily retrievable form.

From this repository we should be able in the future, by the writing of simple special programmes, to obtain a wealth of statistics and a clear idea of the natural history of the disease in this country, and the effect we are having on it. This should give valuable guidance in the planning of future moves in the campaign against tuberculosis.

In conclusion I must pay tribute, and give thanks to the Rhodesian Association for the Prevention of Tuberculosis (R.A.P.T.) and to the General Manager of the Rhodesian Railways without whose help this work would not have been done. R.A.P.T. paid for the printing of the data collection forms and coding sheets and made the initial approach to the General Manager of the Rhodesia Railways, who then agreed to donate the services of the Railways' computer bureau as a charitable donation to R.A.P.T. to assist in the fight against T.B.

The co-operative effort by the public health service assisted by non-government medical personnel, voluntary organisation, and public-spirited private concern, has made this an outstanding community effort in disease control.

My thanks are due to Dr. A. O. Pugh for perusing the draft and advising thereon, and to the Secretary for Health for permission to publish.

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