

shown that the associated mortality is decreased in this group of patients.<sup>19</sup>

**KFC:** What is the role of methotrexate as a steroid sparing agent?

**DMG:** Our recent study showed that low dose methotrexate had a substantial steroid sparing effect in a moderately large group of patients, but not in all patients.<sup>4</sup> It should be reserved for patients with severe side effects from steroids; the side effects of long term methotrexate treatment are not fully documented.

**KFC:** In summary, hormonal factors seem to be important in this case. Asthma symptoms worsened after menarche and there was a close relation between symptoms and menstruation. Suppression of menstruation with progesterone improved her condition, although it resulted in depression and unacceptable weight gain. Prolonged treatment with oral corticosteroid had serious systemic side effects. Methotrexate was introduced as a steroid sparing drug to reduce the risk of further musculoskeletal complications and greatly facilitated control of her asthma; the success of this approach in our patient suggests that a trial of methotrexate may be warranted in young asthmatic patients who are steroid dependent. Monthly bisphosphonate infusions resulted in an appreciable increase in lumbar bone mineral density.

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## How To Do It

### Design a clinical information system

A P Smith

When in 1989 my department decided to get a clinical information system we quickly realised that we would have to do it ourselves. Everything we looked at was much too expensive and very complicated. Three years and many man hours later our clinical information system, Dossier, is up and running. The system won the personal computer rewards competition sponsored by the Peat Marwick group and the *Guardian* last November. This paper describes the key points we learnt, which should be taken into account when planning a clinical information system.

Dossier is a real time, episode based, clinical information system designed around the daily work of the medical secretary. Clinical data are collected as discharge summaries and outpatient letters are typed, although on a networked system remote work stations could be used to record the presence of a patient, the secretary doing the rest while typing the discharge summary. Because our system is real time, information is immediately available to other users as it is entered, and as it is episode based and records activity as it happens it gives an accurate picture of workload.

#### Who will enter data?

Before starting this project our knowledge of computers was limited to the usual experience of anyone doing clinical research—word processing, simple databases, medical statistics, and so on. But designing and writing this type of computer program is as much about attitudes and philosophy as technique

and the ground rules are simple.

The fewer the people who enter information and the smaller the data set the more likely you are to get a full and accurate record on every case. Our data set (table) is clinically determined and omits items such as provider and purchaser codes, overseas visitor status, NHS number, place of birth, occupation of husband and father, discharge method and destination, and similar information. The choice was determined entirely by availability (who knows their NHS number?) and potential usefulness to clinicians, although we are going to have to include some of the items we originally left out because managers will need them.

When deciding on a data set, you will have to compromise between ease of data entry and demands for all sorts of information, but it is best to exclude information which is difficult to collect. Unfortunately, many recommended data sets are so inflated that no clinical department will ever be able to collect them. It should take no longer to enter a new patient and code into the computer than it takes a secretary to write the letters now, so resist unreasonable pressure to include unnecessary or awkward data items—they simply do not get filled in, or, if compulsory, slow the process of data entry to the point that it becomes irksome.

#### How will data be validated?

Consider how you will validate the contents of your database. Dossier saves the name of the person who last

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*BMJ* 1992;305:415-7

Field	How information is stored (No of characters)	Validation
<b>Data held on every patient:</b>		
Name	Character (30)	Valid if not empty
Hospital number	Alphanumeric (8)	By user. Non obligatory
Address	Character (60)	Valid if not empty
Postcode	Character (8)	Valid if not empty
Telephone number	Character (12)	By user. Non obligatory
Sex	Logical (1)	Valid M/F
Referral type	Character (2)	Valid if not empty. User defined, entry from pop up table of 6 choices
Alive or dead	Logical (1)	Valid if not empty
In or out status	Logical (1)	Valid if not empty
Date of birth	Date (8)	Date validation
Date first seen	Date (8)	Date validation
Date admitted or attended clinic	Date (8)	Date validation
Date discharged or died	Date (8)	Date validation
General practitioner number	Numeric (5)	Created by system
Unique patient identification	Numeric (5)	Created by system. Relational key
Archived flag	Logical (1)	Created by system
<b>Data held when available:</b>		
Diagnosis	Character (76)	Text entered by medical secretary from dictation
User defined field	Character (76)	Defined at set up. Text entered from dictation
User defined field	Character (76)	Defined at set up. Text entered from dictation
User defined field	Character (000.000)	Defined at set up. Text entered from dictation
User defined field	Character (000.000)	Defined at set up. Text entered from dictation
Treatment	Character (152)	Text entered from dictation
Action	Character (20)	Follow up, waiting list, etc
Last seen by	Character (20)	Name of doctor seeing patient
Codes	Character (76)	List of codes generated by coding utility
Text field	Character (64.000)	Full word processor. Contains text for letter
Last altered by	Character (20)	Automatically entered with user's passname if record altered
Length of stay	Numeric (3)	Days calculated and entered automatically
Cumulative outpatient count	Numeric (3)	Counts number of outpatient episodes
Cumulative inpatient count	Numeric (3)	Counts number of inpatient episodes

used a record so we know who is responsible for its accuracy. Because key items of information in the database appear in letters and summaries, validation takes place when these are signed and the signatory is responsible for that patient's record. The program also checks for obvious errors, such as patients getting discharged before they are admitted, and will not permit the user to exit a screen until all essential items are entered correctly. Dossier comes with an archive utility to store defunct records on a floppy disk and a range of other utilities including hard disk back up and restore. Most users would probably prefer to use a tape streamer for back up, especially as the size of the database increases, and this would be essential on a networked system.

#### Will the system overburden staff?

Think of your secretary. You will get no extra staff to run your computer. No system should increase secretaries' workload, instead it should make them more efficient and happy. The most important person is the one who puts the data in, and like it or not that will be somebody in your office, maybe even you. Collecting information is boring and disruptive so make it agreeable, and there must be an immediate and perceptible benefit. Medical secretaries are the primary beneficiaries of our system, the audit and managerial data are its byproducts. The system contains useful gadgets such as automatically remembering and typing general practitioners' names and addresses, a word processor, interactive diagnostic and procedure coding, a "quick patient look up" facility, and a cache of every letter ever written on any patient, which is useful if the notes go missing; the system simultaneously stores the information clinicians and managers need. While these features help the secretaries in their work they ensure accuracy too.

#### Use local skills

Maximise on the local clinical experience. Members of information technology committees should ferret out clinicians in their district who have already set up their own systems, and there are a lot of them about. It

is important that their experience and enthusiasm be harnessed and spread to their colleagues because the idea that data collection and validation is as much part of clinical work as outpatient clinics or theatre has not generally caught on. Most doctors think it will all be done by someone else, but most of the work will be in doctors' offices so be sure that a proposed system has been well and truly tested by real doctors and that it is acceptable in the clinical setting. Designing your own system ensures complete acceptability, of course, but not everyone will want to repeat our experience.

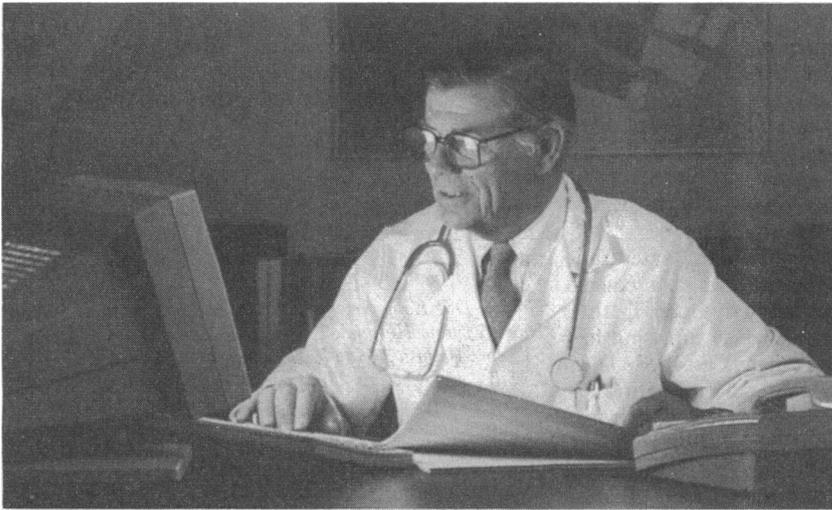
Big computers are to be avoided. Mainframe or mini based applications are expensive and specialists are needed to keep them going. Installing personal computers is the cheapest way. At only a few hundred pounds they are cheap enough to throw away if they stop working, and their programming tools are inexpensive and can be used by ordinary people. We chose dBASE, got the ideas working, then switched to Clipper 5, which is less friendly but more powerful. Doctors and secretaries were involved early on and a working program containing all the essential features was put into daily use. Later we employed a computing student from the University of Sussex during his vacations to provide the special expertise. Your solution should avoid the need for expensive hardware and software engineers. You will always want to add new features or modifications as it is impossible to plan a computer system in detail from scratch, and it should be possible to add these locally without great expense. The idea that you can have a cheap clinical information system running on personal computers is perfectly tenable provided that you keep it simple and decide what you really want.

#### Don't be overambitious

Keep to essentials and do not try to do things which can be done better or more cheaply another way. A clinical information system collects clinical data, gives you reports, and recalls patients for audit. Ours also stores all the old letters and case summaries and does the coding. Don't ask it to do anything else. The number of data items required for these purposes is quite small and so this is ideal for personal computers. One reason that existing commercial systems are so expensive is that they are too big and do too much.

Consider installing single user systems. Although low tech this solution encourages people in the habit of data collection and very quickly puts the means to do so on their desks. There can be few circumstances when a clinician would want to have direct access to a colleague's clinical database, and there is no reason for managers to have that privilege either; if the database is located in the consultant's office ownership and data security are assured. As long as the information is being collected it doesn't really matter where it is kept. Single user systems could be on every consultant's desk for less than £3000 each, including hardware; the most expensive single item would be a good printer. In these terms it is incredible that all hospital doctors do not have this facility now; the reason they do not is that single user systems are not interesting to managers. Once we had started using Dossier we also soon wanted to share data on a departmental basis. We compromised on our reluctance to let the data leave the consultant's office and wrote a networked departmental version, but this is as big as it should get—any bigger and costs rise, with diminishing returns.

Of course, some managers and most information technology advisors would prefer a single hospital clinical database, but their perceptions of the advantages, and the resulting costs, have slowed the introduction of systems for everyday clinical use, and it places too much power in the information technology



All hospital doctors should have a clinical information system on their desk

manager's hands. Naturally, managers must have the information but they do not need direct access to a clinical database to collect it. At the simplest level a floppy disk sent in the internal mail to put on the administration's computer each week would achieve the same object, although a networked poll of departmental databases is better but is considerably more expensive. In our hospital, management has been supportive in installing clinical systems but so far has shown little interest in developing them on a hospital-wide basis. This will come, however, and future projects for Dossier include a suite of management functions that will be able to collect information from departmental databases across a hospital network.

Single user or departmental solutions have many advantages. Everything stops when a hospital or district computer breaks down so it needs elaborate back up and maintenance arrangements; it is inconvenient if a smaller system fails but life goes on. Personal computer databases can be read, copied, analysed, and manipulated by all sorts of tools, so you are not locked into any particular application and can change if anything better comes along. The simpler they are though, the greater the risk of unauthorised access, which of course is another argument for keeping it on the consultant's desk.

#### Build in flexibility

By now our intentions will be obvious: to free clinical users from the constraints of cost, computer experts, managers, and those who think they know best. Such freedom is essential to independent people whose data requirements vary widely. A system which imposes on or interferes with daily life will not be tolerated for long, and if the system is only tolerated it cannot be relied on. We believe that clinicians, whose data requirements inevitably differ, must be able to decide what they want to collect within the limits of a common data set. Our system contains fields whose functions are defined by the user on setting up for the first time, and experience has shown that we could possibly do with more.

Reporting also needs to be flexible because most people don't know the questions they will want to ask. We designed a flexible report builder which is simple enough for doctors and their secretaries to use. It allows you just to browse, which helps to formulate ideas about disease patterns—for example, the incidence of asthma referrals from a particular postal district. Alternatively, it can report in lists, synopses (statistical reviews showing subsidiary diagnoses, age and sex breakdown, referral types, and source), episode audits (statistics of inpatient and outpatient episodes with length of stay), and counts according to any item,

or combination of items, in the database subject to logical analysis. To be really useful a system must permit clinicians to get at their own information whenever they like and play with it.

#### Benefits of the system

So we can now audit our work, wards, and clinic, and the work of juniors. We have reduced the numbers of ineffective follow up appointments and we discharge patients earlier. For the first time, because of smaller clinics, we can run a proper appointments system; this was an unexpected bonus and the first benefit we noticed. We can investigate the causes of repeat follow up visits and of readmissions, and by relating procedures to diagnosis and length of admission we can assess the use of resources per case.

Computers are great at assessing the use of resources, comparing workloads, treatments, and patterns of work, but is this really clinical audit? To clinicians audit means the examination of practices, modifying them, and reviewing them later to ensure that modifications have been followed and are effective. If you cannot recall information about your patients you cannot audit them, and in this sense computers are useful in clinical audit. But otherwise they are not required. Doctors must be clear about this, clinical information systems contain a relatively small data set on a large number of patients. By contrast audit needs a lot of information, which varies from audit to audit, on a subset of patients; until the audit is planned the data to be collected are not known. So do not harbour unreasonable expectations about the role of computers in audit. A surgeon might collect data about wound infection rates, and his system could list the patients concerned, but why they got infected and what action should be taken is something he must decide for himself. All the computer can do is identify the patients for study.

#### Limit the computers' functions

One reason that computers are not generally available to hospital doctors is the impression that they must do everything—audit, office automation, management functions, case mix, keep the waiting lists, and so on. Do not fall into this trap, if you do you will never get your system. Keep it simple, adopt an evolutionary stance, and make sure that clinical and secretarial needs are met first. Remember too that a clinical database requires a cultural shift which is greater than most doctors understand. It means pride in owning the data, confidence in its validity, freedom to explore and understand it, and an absence of computer bureaucracy. Of course not all doctors are interested in information technology, and you may be content with whatever comes along. But never underestimate the disruptive potential of a computer.

By doing it ourselves we learnt a lot about audit, coding, and data collection. It took three years, about the same commitment as a major clinical research project, and cost about £6000. There is not an existing system at the price. Unless a lot of new money is made available most hospital doctors will not get computers for clinical use within the reasonable future. But why wait for your information technology advisory committee to buy you a white elephant? Cheap, practical systems are available now: get started, get the experience, feel the enthusiasm grow, and you will then be able to talk to the specialists on equal terms. Who knows, you may be able to inject some clinical commonsense into the tangled world of hospital information technology.

(Accepted 2 April 1992)