

# In confidence?

*Do regional databases make it impossible to offer a truly confidential service?*

IN 1989 THE Department of Health asked all regional health authorities to set up a database "to monitor trends in drug misuse and the use of drug misuse services". All regions have now established a system for agencies to complete a form on new client contacts and return these to a regional database manager. All but one – South West Thames – require data capable of identifying individuals – 'attributable' data.

But there is a dilemma. Many drug services market themselves as 'confidential' and place a premium on protecting clients' rights – essential to their abilities to attract clients and achieve national harm reduction/treatment objectives. To make these claims credible they need to stop data that identifies individuals going outside their services. Such concerns have led some agencies to refuse to supply their regions with the full data requested, meaning their caseload is lost to the reporting system.

On the other hand, if personal identifiers are withheld, the database manager cannot prevent double counting – where a single client attending more than one agency is recorded as two or more clients, misleadingly inflating the figures. What should we do?

## The options

There are three types of reporting systems: event reporting; case reporting; and case registers. Each has its own advantages and disadvantages.

An **event reporting** system simply reports incidents of (in this context) help being sought for a drug problem, without identifying individuals. It can alert policy makers and agency staff to emerging drug use phenomena such as the use of new drugs or new routes of administration, acting as a kind of early warning system. It can also be used to monitor trends and help assess the impact of preventive programmes, media campaigns, etc.

Event reporting systems cost relatively little and there are no confidentiality problems as identifying information is not needed. There are fewer maintenance problems than with more demanding

systems and less need for highly trained, specialised operators. The Drug Abuse Warning Network (DAWN) in the United States is an excellent example of a successful event reporting system which has been in operation for many years.

The limitations of an event reporting system arise from the lack of individual identifiers. This makes it impossible, for example, to track a cohort of cases to determine which agencies they contact. Nor is it possible to count 'events' as 'heads', unless there is an internal check on whether the same individual has been reported twice.

Systems incorporating such a check are known as **case reporting** systems. These need an attributor unique to each individual, though it need not actually identify them – date of birth plus initials might do. In this sense it can be both anonymous and capable of 'recognising' when it comes across the same individual twice. This prevents double counting and permits a client's progress to be tracked. CODAP (the Client Oriented Data Acquisition Process) in the United States is an example of this type of system.

by

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SW Thames RHA is the only region operating a drug misuse database which does not require 'attributable' data to avoid counting the same person twice at different agencies. It is argued that such data is not needed to achieve the aims of the database initiative and that collecting it jeopardises confidentiality because it could be used to identify individuals. Requiring it excludes data from some (especially low threshold) services which are unwilling or unable to collect personal details.

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The problem arises when the agency's records are fed into a central database or, indeed, passed to any other agency, raising the possibility of matching that data with the third type of system – the **case register**. Registers *do* contain full details including identifiers such as names and addresses. The Home Office's Addicts Index is the best known example in the drug misuse field. The problem is that partial data from a case reporting system could be matched with the full data in a register, effectively 'decoding' the anonymous agency attributor.

Most agencies would probably accept a database system that cannot fully avoid double counting, if this was the only way to guarantee confidentiality and with it the credibility of services. However, the Department of Health will not feed records into its central database unless they are based on attributable data – usually initials and date of birth.

The goals of the database initiative have moved away from event reporting (which does not require personal identifiers) to case reporting (which does). The limited steps taken in this direction perpetuate the disadvantages of both systems: double counting is still possible if people use different names/dates of birth at different agencies; and significant ethical problems and human rights infringements are created by demanding even these minimal attributors.

## Are attributors needed?

The argument for attributable data *seems* self-evident: drug users present at several agencies, so some form of personal identification is needed to avoid double counting. But this argument is acceptable *only* if the problems of the population being studied are legal and free from stigma, *and* if the outcome will be an accurate assessment of the extent of drug problems.

Clearly such an assessment is not possible from the databases. As presently constructed, drug misuse databases can only provide an estimate of the number of drug users coming forward to helping services. Insisting on identifying these individuals

