TOWARDS A NATIONAL DRUG DATABASE

The North West has pioneered a revolution in drug misuse data. Now the revolution's coming your way. The chief architect explains.

The Department of Health has instructed RHAs to establish drug misuse databases and recommended they adopt the system developed for the North West. The system's originator explains that it preserves client confidentiality while gathering information on a much wider range of drugs and from a much wider range of services than any previous national system. The self-carboning forms can also be used for agency records.

Michael Donmall

The author heads the Drug Research Unit at the University of Manchester which created the Drug Misuse Database being used in the North Western RHA and now recommended for national adoption by the Department of Health.

THE DEPARTMENT of Health has announced that each regional health authority will be setting up a local drug misuse database modelled on the system developed by the Drug Research Unit in Manchester. On 3 November Health Secretary Baroness Hooper described this as "a very important step forward. If we are to tackle the problem of drug misuse successfully it is essential that we have better information about the pattern of drug misuse and the impact of services".

On the same day a circular was issued requiring each region to implement a drug misuse database by 31 March 1990, and to arrange for a return to be made for at least one district by November 1990.[1]

What does this mean for drug services? What is the information to be used for and by whom? How can we protect the rights of the individual? I will try to describe what the database is and what it is not; what it can, and what it cannot achieve.

The North West's Drug Misuse Database grew out of research funded by the DHSS to evaluate the introduction of community initiatives into drug services in the region.[2] Its practical utility in providing agencies with detailed, anonymous information led to its permanent establishment by the North Western Regional Health Authority and also to support from the Department of Health to adapt the system for use in the other regions of England.

Especially in a field afforded considerable media attention, lack of good information often results in the spread of misinformation. What can we say about the drugs misuse problem in our local community and the users presenting to services? For example, what proportion of the using population is known to be injecting?

Basic questions such as this must be asked by all agencies to improve the targeting of local and national services. The information base on which such questions are answered is often inadequate; we have relied on the development of local projects to inform planners and politicians at every level about a subject high on the agenda of every caring agency since the beginning of the decade.

The official picture of drug misuse in this country is largely informed by two sets of annual statistics:

— Department of Health drug misuse statistics which report regionally on admissions to mental illness hospitals with drug related diagnoses; and

— Home Office statistics on the misuse of drugs which report by police force area on notifications of addiction made by doctors and on figures relating to police activity.

Neither is particularly useful for answering questions relating to trends in known drug drug users or the utility of services — both essential for planning. Very few drug misusers are admitted to hospital, while notification is required only of doctors (from whom compliance is often poor) and covers only the opiates and cocaine.

Neither of these figures can give a detailed local picture and both are restricted to the work of doctors. Figures relating to drug offences and seizures are dependent to a considerable extent on enforcement policy and deployment and contribute little to health service planning.[3]

The new database

The Drug Misuse Database overcomes many of the problems of existing statistics by providing a means of routinely monitoring the numbers and profiles of individuals who attend a range of services with a wide range of drug-related problems.

The Drug Data Pack to be made available to each region provides everything needed to set up a basic version of the database operated in the North West. It provides guidelines on implementation, templates for the data collection sheets, detailed notes on coding and avoiding double-counting, and, of course, the software package itself with an operating manual — everything except the hardware and the local will — these must be provided by the end-user.

IN CONFIDENCE: Please read notes on the back

NORTH WEST DRUG MISUSE DATABASE and **NOTIFICATION OF DRUG ADDICTION**

Local Monitoring of Problem Drug Use — Misuse of Drugs Act, 1971

Health Authority Code: P | Home Office Code: | For Database use only: Ref: | Date in:

Telephone Enquiries: 061-798 0544 — Telephone Enquiries: 01-273 2213

Please complete a form for every patient whom you attend, who has a drug problem of any kind. The notification part of the form should only be sent to the Home Office if the person is notifiable. Please use BLOCK LETTERS and Ball Point Pen.

Details of Patient

First Name(s) — Last Name — Alias or Maiden Name
Address — Date of Birth — Male ☐ Female ☐ — NHS No.
Postcode — Ethnic Group

Employment: Present or last occupation — Employed ☐ Unemployed ☐ How long unemployed?
Referral From: Self ☐ GP ☐ Probation ☐ Family/Friend ☐ — Psychiatrist ☐ Drug Team ☐ Other, specify
Notification: Is this person notifiable in accordance with the Misuse of Drugs Act 1971? Yes ☐ No ☐ — If so, state which drug(s)

Drug Profile Past Month: include each drug used, prescribed or not (if drug free list significant prior use)

DRUG NAME		PRESCRIBED OR NOT Yes/No/Both	HOW OFTEN (times per day/wk/month)	HOW MUCH (quantity or cost per session)	ROUTE	DURATION (of this drug episode)	AGE OF 1st USE
MAIN DRUG							
DRUG 2							
DRUG 3							
DRUG 4							
DRUG 5 /alcohol							

Is person drug free? Yes ☐ No ☐ If Yes, how long? (See notes)
Injected in past month? Yes ☐ No ☐ Ever injected? Yes ☐ No ☐
Shared needle/syringe in past month? Yes ☐ No ☐ Ever shared? Yes ☐ No ☐

Action Planned

Plan at onset: Nil action ☐ Planned O/P treatment ☐ Planned I/P treatment ☐ Further appointment ☐ — Referred on ☐ specify where — Liaison with ☐ specify who/where
Prescribing plan: Nil ☐ Non-opiate drugs ☐ specify — Methadone DTF ☐ or other forms, specify — Other opiates ☐ specify — Anticipated duration of prescribing — Is this a reducing dose? Yes ☐ No ☐ Don't know ☐
Prescriber, if not yourself: GP ☐ Psychiatrist ☐ Drug Team Doctor ☐ Other

Details of Reporting Doctor

Name:
Patient seen in/at/by: General Practice ☐ Hospital Outpatient ☐ Hospital Inpatient ☐ Police Surgeon ☐ — Prison Med. Service ☐ Other, specify
Treatment Centre/ Hospital/Practice: Name/Address — Postcode — Tel — Date Seen

▶ This is your copy to retain

Drug Research Unit (University of Manchester) 061-798 0544 — 5989/9 M

IN CONFIDENCE: Please read notes on the back — **NORTH WEST DRUG MISUSE DATABASE** and **NOTIFICATION OF DRUG ADDICTION** (sheets two and three; personal details blacked out)

NORTH WEST DRUG MISUSE DATABASE

Local Monitoring of Problem Drug Use

Is Client new to this agency? Yes ☐ No ☐ — Type of Contact: Letter ☐ Telephone ☐ Face to face ☐ — Appointment: Made? Yes ☐ No ☐ Attended? Yes ☐ No ☐ — For Database use only: Ref: Date in:

BLOCK LETTERS Please read the notes on the back

Details of Client

First Name(s) — Last Name — Maiden Name
Address — Date of Birth — Male ☐ Female ☐ — Postcode — Tel
Area of Town — Ethnic Group

Employment: Present or last occupation — Employed ☐ Unemployed ☐ How long unemployed?
Referral From: Self ☐ GP/Psychiatrist ☐ Probation ☐ Family/Friend ☐ — Drug Clinic, specify — Other, specify
Living With: Drug user(s) ☐ Non-drug user(s) ☐ Parents/Partner ☐ Living alone ☐
Dependant Children: None ☐ Number with client ☐ No. living elsewhere ☐ Number in care ☐
Drug Related Contact: (in past 12 months) None ☐ GP ☐ Psychiatrist ☐ Probation ☐ — A&E ☐ Social Services ☐ Vol. drug agency ☐ Private Doctor ☐ — Drug Team/Clinic, specify — Other, specify
Housing: Please summarise
Current Legal Situation: Please summarise

Drug Profile Past Month: include each drug used, prescribed or not (if drug free list significant prior use)

DRUG NAME	PRESCRIBED OR NOT Yes/No/Both	HOW OFTEN (times per day/wk/month)	HOW MUCH (quantity or cost per session)	ROUTE	DURATION (of this drug episode)	AGE OF 1st USE
MAIN DRUG						
DRUG 2						
DRUG 3						
DRUG 4						
DRUG 5 /alcohol						

Is person drug free? Yes ☐ No ☐ If Yes, how long? (See notes)
Injected in past month? Yes ☐ No ☐ Ever injected? Yes ☐ No ☐
Shared needle/syringe in past month? Yes ☐ No ☐ Ever shared? Yes ☐ No ☐

Action Planned

Plan at onset: Advice/information ☐ Further appointment ☐ No further action ☐ — Referred on ☐ o/p ☐ i/p ☐ specify where — Liaison with ☐ specify agency — Prescribed detox ☐ Non-presc. detox ☐ Other presc.
Prescriber: GP ☐ Drug Team doctor ☐ Psychiatrist ☐ Other

Details of reporting agency

Your name: (print) — Job Title
Agency: Name & Address — Tel — Date of Contact

▶ This is your copy to retain

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▲ **The North West's database form for doctors with sheet two to be used for notification to the Home Office (only for opiate or cocaine addiction) and sheet three to be sent to the RHA's database. Note how some of the information on the top copy (for the doctor's records) is blacked out on the other two forms.**

◀ **The version of the form for non-medical agencies also includes an undercopy (not shown) to be sent to the RHA database which blacks out name and address. Social information on the client replaces some of the medical information on the doctors' form.**

The database operates at several different levels. It is as much for service providers as it is for service planners, because one of its most important functions is to feed information back to the agencies themselves. It also satisfies the Department of Health's central requirements and the Home Office notification procedure, minimising the amount of form filling required.

Its main characteristics are that:

— the records are anonymous as far as the drug user is concerned;

— it applies equally to non-medical and medical agencies;

— it covers most drugs, not just the opiates and cocaine;

— it allows for local agency feedback of a comprehensive dataset;

— it allows Home Office notification where appropriate.

How it works

All medical and non-medical agencies are supplied with one of two alternative sets of database forms — one for medical agencies, one for non-medical (see illustration on page 11).

The three-part medical form consists of:

— a top page to be kept by the agency for use as a summary for patient or client notes;

— second page for Home Office notification if appropriate; and

— a third page which generates data for the database.

Only the top copy is written on. The undercopies are self-carboning, but selectively eliminate data that is confidential or irrelevant. Thus the Home Office page excludes information not required under the Misuse of Drugs Act, while to achieve anonymity the database page includes all the information except name and address. The pages are colour-coded for ease of use and reply-paid envelopes are supplied to encourage returns.

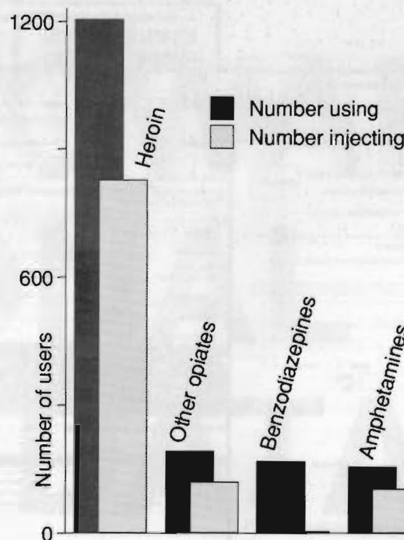
The non-medical database form is similar but consists of just two pages — one for agency notes and one for the database. Sections of the form specific to medical matters (prescribing action, etc) are replaced here by social data such as legal status, contact with other agencies and number of dependent children. In the North West the non-medical system is used by statutory and non-statutory agencies including the Lifeline Project, local therapeutic communities and all 20 community drug teams; the medical system is used by all doctors in the region.

Training and support

Initial training courses for regional managers and database operators have already been held and will be repeated if necessary. The North Western RHA is offering a package of follow-up support including: copies of the region's database software and manual; a newsletter; visits by experts to help set up local systems; coordinating meetings; help in accommodating local modifications to database forms.

It's also envisaged that a database user group will be formed to discuss issues and recommend improvements.

Details from Michael Donmall on 061 798 0544.



How use of some drugs looked in the North West in 1987. Much more information can easily be extracted from the database.

The 'front end' of the Drug Data Pack provides a straightforward means of entering data into a sophisticated 'relational' database structure. The software automatically adds new treatment episodes to the user's file. Most double-counting is avoided by reference to a person's initials, date of birth and sex, but the database operator is automatically alerted to close matches in case they are, in fact, the same person.

Information can be retrieved through pre-programmed summary tables covering age/sex, employment and main drug and total drug profile, including percentages known to be injecting and average ages. These retrievals can be made for selected districts or agencies between any chosen dates. The operator is 'menu-led' through these procedures. Used with the manual, the process is straightforward even for inexperienced computer users.

The database can also be interrogated using other commercially available packages such as dBase, FoxBase or SPSS, depending on local needs and expertise. Its full potential is realised with this method, but the basic package will give more than enough information for most purposes.

At set-up, the database manager/implementor is able to customise the system by inserting their own region's district and agency names and by determining passwords that allow different levels of access. Thus it may be desirable to allow one person to edit and/or retrieve data from the system, while another may be given access only to 'display' mode.

Version 1.0 of the software does not allow regions or agencies to add their own data categories, but upgrades being developed will allow this, increasing local flexibility.

Experience in the North West and in the East Sussex pilot scheme has shown that a considerable investment in both time and effort is initially required to make the system known to agencies and to fully explain how it works.

Because of this it is suggested that the databases should be introduced in two phases. Phase one will involve all doctors and all 'specialist' drug services, statutory or non-statutory. Phase two, not envisaged to start until next summer, will involve other 'generic' services such as probation and social services.

The Department of Health has also suggested that regions should start by implementing the system in at least one district rather than attempting to involve the whole region from the start.

Confidentiality

Two important points should be made about confidentiality. Firstly, the full names and addresses of drug users are not sent to the database, so there can be no question of identification. Secondly, the computer system can be well protected by passwords, making it very difficult for an unauthorised person to gain access. In any case, the personal information stored in the database is not half so sensitive as that routinely kept by any GP or community drug team. Registration with the Data Protection Registrar protects both the individuals represented in the database and those operating the system.

It may also be useful to set up a local steering group, with representation from contributing agencies, to discuss the use of retrieved data. However, our experience over more than three years has been that any initial ethical concern is completely allayed by the genuinely anonymous nature of the user data that is stored and fed back.

IT IS IMPORTANT for service providers and planners to be aware that, for evaluation purposes, the database can describe only a part of the total drug-related work done by drug teams, agencies or doctors. Non-client work such as liaison, training, etc, will need to be assessed by other means. However, the database can provide a major part of the routine monitoring for an agency.

Also the database should not be thought of as portraying the total picture of the extent and nature of problem drug use 'out there', but as a window into that picture — a piece or two of the total jigsaw. ■

1. Department of Health. Health Circular HC(89)30.
2. Donmall M. *et al. The introduction of community-based services for drug misusers: impact and outcome in the North West, 1982-1986*. A report to the Department of Health, 1989.
3. *Druglink*: 1989, *4*(6), p.5.