



***National Treatment Agency
for Substance Misuse***

National Drug Treatment Monitoring System (NDTMS)

Confidentiality Toolkit

Author M. Bell / NEPHO
Date August 2009
Version 4.1

Revision History

Version	Author	Purpose/Reason	Date
1	M. Bell	Initial document	
2	M. Bell M Roxburgh	Updated to include information on Drug Intervention Programme	July 2005
3	M. Bell	Updated to include reference to alcohol data collection	June 2007
4	M. Bell	Document updated to include new corporate layout, text corrections and additional clarification and guidance.	June 2009

External References

Ref No	Title	Version

This document uses the convention that any external references are indicated by square brackets e.g. [3]

Outstanding Issues

Issue No	Doc Section	Description

Significant Changes in this Issue

Change No	Doc Section	Description
1	Help Sheet 3	Now includes reference to obtaining retrospective client consent from services new to NDTMS
2	Help Sheet 4	Wording has been totally revised and now includes information on sharing of Treatment Outcome Profile (TOP) data
3	Help Sheet 7	Wording has been revised to include information on record retention.
4	Help Sheet 8	Style has been updated and additional information included relating to: <ul style="list-style-type: none"> • Sharing of data across services • Local arrangements for collecting full post codes • Record retention • Register of addicts

National Drug Treatment Monitoring System (NDTMS)*

CONFIDENTIALITY GUIDELINES FOR STAFF

Introduction

Staff within drug and alcohol treatment services often have anxieties about sharing information with other organisations, even if those organisations are part of the National Health Service. Rightly, there are concerns about client/patient confidentiality. The following help sheets are designed to assist treatment services to deal with this issue. The sheets briefly discuss:

1. NHS Code of Practice
2. Treatment Service Confidentiality/Data Handling Policies
3. Sharing Drug and Alcohol Data with the National Drug Treatment Monitoring System (NDTMS)
4. Data Sharing Protocols
5. Why information is needed for the NDTMS
6. How information is handled within the NDTMS
7. What type of information is collected for the NDTMS and how long it is retained for

There is also a sheet that can be used to pass information on to clients/patients about why their information is needed, both by the treatment service and for the NDTMS:

8. Information for Clients/Patients

*Although the name 'NDTMS' has not been changed, the NDTMS now includes the collection of both drug and alcohol treatment data. The term 'NATMS' (National Alcohol Treatment Monitoring System), used by some organisations when specifically referring to collection of alcohol data, is synonymous with NDTMS.

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 1

NHS Code of Practice

Sharing information is part of good communication and is vital to the health care process. Nevertheless it has to be done with due consideration for client/patient confidentiality. The Department of Health has produced a code of practice for NHS staff that addresses confidentiality issues. Voluntary and private drug and alcohol treatment services may also find this code useful to inform their own policies. The document 'Confidentiality: NHS Code of Practice' can be found on the Department of Health website at www.dh.gov.uk

Search 'NHS confidentiality code of practice' or 'Patient Confidentiality' for this and other information. The website also provides details of how to apply for hard copy publications.

National Drug Treatment Monitoring System (NDTMS)

CONFIDENTIALITY GUIDELINES FOR STAFF

HELP SHEET 2

Treatment Service Confidentiality/Data Handling Policies

All drug and alcohol treatment services must have a clear confidentiality/data handling policy, which is understood by all members of staff. If you have not seen such a policy, ask where it is located.

The policy should be presented and clearly explained to the client/patient, both verbally and in written form, before assessment for treatment begins. The policy may be outlined in the form of a simple leaflet and/or notice displayed within the treatment service. It should be explained on the client/patient's first visit and must describe:

- what information will be collected by the treatment service
- when and what information will be shared with any other services and organisations involved in their care
- who the information will go to and why
- in what circumstances confidentiality may be breached.

For services within NHS Trusts, the policy may be part of a general Trust policy, but it should be adapted if it does not include the above information.

Help sheets 4, 5 and 6 may help you to devise a policy if you do not already have one.

Help sheets 5, 6 and 7 outline the when, what, who and why as far as sharing with the National Drug Treatment Monitoring System (NDTMS) is concerned - but you will doubtless have other services and organisations with whom you may be sharing data.

The information on Help sheet 8 can be communicated to clients/patients as is, or can be incorporated into your treatment service policy. It describes why client information is needed, both by a treatment service and for the NDTMS.

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 3

Sharing Drug and Alcohol Data with the NDTMS

Local confidentiality policies may differ due to the different needs and practices of drug and alcohol treatment services but, in the case of information collected and shared with the NDTMS on behalf of the National Treatment Agency for Substance Misuse (NTA), the following should provide some guidance.

- A client/patient's initials, date of birth, gender and part postcode are used for the national NDTMS. Although not fully identified data, these items of information still make it necessary to obtain explicit consent[†] from the client/patient before collecting data to send to the NDTMS.
- Ideally, this consent would be part of the process of obtaining consent in general, when explaining local data collection policies.
- The patient/client MUST be given the NDTMS information sheet (see help sheet 8), alongside the treatment service's confidentiality policy/leaflet, which explains what the information will be used for.
- If the client/patient refuses consent, record REFUSED in the patient record.
- If a treatment service has not previously provided data to the NDTMS but begins to do so for the first time, the service should seek retrospective consent from any existing clients. Where consent cannot be obtained, then mark the record as 'no consent'.
- Most clients/patients are reassured when they know why their data is collected and how it is shared. Become aware of the reasons for collecting various data items and how information is used within your service so that your clients/patients are fully enabled to make an informed decision.

[†] Explicit consent is usually given orally or in writing. It should be freely given in circumstances where the client has been appropriately informed. There should be an understanding of available options and any concerns and queries should have been addressed.

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 4

Data Sharing Protocols

Having data sharing protocols in place, that outline how and why data is shared within and between organisations, is good practice.

It may be that local collection procedures involve third parties (e.g. Partnerships) to make use of jointly procured software. This may necessitate information sharing across treatment services and/or Drug/Alcohol Action Team (DAT/DAAT) regions.

It may be that certain treatment services share software across all their sites and information is therefore shared within these sites and/or beyond the region.

It may be important, for one reason or another, for treatment services to share client/patient data if there is more than one service simultaneously providing treatment, irrespective of the Partnership or the software used. This is relevant to Treatment Outcome Profile (TOP) data where a treatment service should, subject to permissions and data sharing protocols, send copies of the TOP information to other services.

Service Managers should ensure that data sharing agreements are in place, as this is the responsibility of the treatment service that is collecting the data. They should also take care to ensure that clinical and administrative staff are fully aware of, and understand, the way in which data is used and shared. In turn, this information should be passed on to clients/patients who should feel reassured about the confidential nature of the data collection and sharing processes.

If your service/Trust does not already have data sharing protocols in place, there are useful websites at www.justice.gov.uk and at www.ico.gov.uk. These are the websites for the Ministry of Justice and the Information Commissioners Office respectively.

Guidance and example protocols are also easily accessible using internet search engines by typing in 'data sharing protocols' for guidance, or 'NHS data sharing protocols' to produce a list of example protocols currently being used by different NHS organisations.

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 5

Why Information is needed for the NDTMS

The drug and alcohol treatment information that you provide to the NDTMS is used for several purposes. Primarily it is used to:

- Assess the number of individuals attending drug and alcohol services in order to monitor the progress of the national drug and alcohol strategies.
 - Evaluate the efficiency and effectiveness of drug and alcohol treatment provision, including treatment outcomes for clients/patients.
 - Monitor the use of resources. This helps ensure equitable funding of drug and alcohol treatment services nationally.
 - Provide a local and regional picture of drug and alcohol users and their needs, which will assist service commissioners such as Drug/Alcohol Action Team (DAT/DAAT) Partnerships, Primary Care Teams and Local Authorities in planning and developing better drug and alcohol treatment services that are more appropriate to their geographical area.
 - Produce statistics and to support research on drug and alcohol use, treatment or general public health.
-

National Drug Treatment Monitoring System (NDTMS) CONFIDENTIALITY GUIDELINES FOR STAFF

HELP SHEET 6

How Information is handled within NDTMS

Familiarise yourself with the information below and feel free to share its detail with clients/patients who wish to have more information about the NTA and the way in which they handle and use data.

- The NTA is a Special Health Authority and therefore an NHS organisation. It was set up to ensure that clients/patients receive more treatment, better treatment and fairer treatment. The NTA collects information via the NDTMS.
 - The information is passed monthly to NDTMS regional centres or, for some treatment services, it may go to the NTA direct. It may go via a third party (e.g. DAT/DAAT). However, the help sheets do not cover the consent arrangements required for any local data collection arrangements. These are the responsibility of, and should be managed by, the local third party body collecting the data.
 - To minimise double counting, it is necessary to be able to identify if clients/patients have attended more than one service. For this purpose the initials, date of birth and gender are recorded. These data items are stored on a database in a secure environment.
 - Care is taken at the NDTMS regional centres and the NTA to ensure that data cannot be accessed unless it is for a clearly authorised purpose.
 - The law strictly controls the sharing of very sensitive personal information. Anyone who receives information from the database is under a legal duty to keep it confidential.
 - The Department of Health (DoH) gets anonymised information centrally to monitor the national drug and alcohol strategies.
 - Any information published by the DoH, the NTA or NDTMS regional centres is always in the terms of total numbers of people.
 - Any research that would involve the use of data would be closely scrutinised by the NDTMS Regional Centre and/or NTA. Where appropriate, research proposals would also have to obtain ethical approval.
 - Data is matched from NDTMS to identify individuals who enter treatment as part of the Drug Intervention Programme (DIP). All data matching is conducted centrally by the NTA and only aggregated data is shared with the Home Office.
 - Under no circumstances is potentially identifiable data made public.
 - Data is not placed on any register of addicts – no central register exists.
-

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 7

The type of information collected for NDTMS and the time it is retained

It is important that the NHS offers the right treatment at the right time. It is also essential that treatment meets the different needs of the various local and regional populations. For this reason, the NTA seeks several data items. These include the dates of referral, treatment start and discharge. The list incorporates information on the type of treatments offered, as well as the outcomes of treatment. In addition, the main and secondary problem substances are collected, and the NTA also needs to know about demographics, gender and ethnicity.

The information helps the NTA, and/or those who commission services, to use resources more appropriately to improve drug and alcohol treatment throughout the country.

The NDTMS will hold client/patient information for at least 8 years.

Many items of data are needed by the National Treatment Agency (NTA) and some National Drug Treatment Monitoring System (NDTMS) centres have made local arrangements to collect some additional items. In the North East, the regional NDTMS centre is based at the North East Public Health Observatory (NEPHO). Please contact NEPHO (see link below) if you wish to confirm the additional data items currently being collected in the North East region. The data is held securely and indefinitely for current and future analysis, for research purposes.

<http://www.nepho.org.uk>

National Drug Treatment Monitoring System (NDTMS)
CONFIDENTIALITY GUIDELINES FOR STAFF
HELP SHEET 8

Information for Clients/Patients

The information on this page can be adapted, as necessary, by your treatment service. The information on the last page must be imparted to clients/patients either as it is, or included as part of your own service policy.

- We, your treatment service, ask you for information so that you can receive proper care and treatment.
 - We keep your information, together with details of your care, because it may be needed if we see you again.
 - You have the right to apply for access to any records kept about your health.
 - Sometimes this treatment service may need to share certain information (for example on the outcome of your treatment) with other treatment services involved in your care, and as part of your continuous treatment journey.
 - The sharing of sensitive personal information is strictly controlled by law. Anyone who receives information from us is also under a legal duty to:
 - only use the information for the purposes you have agreed to
 - keep the information strictly confidential.
 - We share some information about you with the NDTMS. This is the database used to collect information on drug and alcohol treatment provision. It is managed nationally by the National Treatment Agency for Substance Misuse (NTA), the NHS body responsible for collecting drug and alcohol data and for overseeing drug misuse treatment in England.
 - The following sheet contains more information about NDTMS.
-

Information for Clients/Patients

National Drug Treatment Monitoring System (NDTMS)

- The NDTMS system involves collecting information about the type of treatment you receive from a treatment agency. Sometimes you may be seen by more than one agency. Consequently, to avoid duplication of reporting, NDTMS may share a minimal amount of information about you between the agencies from whom you may have received treatment.
 - Your full name and address are NOT passed on to NDTMS (or the NTA) although some details are sent (e.g. your initials, date of birth, gender and part postcode) to minimise the risk of you being counted twice.
 - In some regions, the full postcode is collected by the NDTMS but this is only for regional use. If you agree to provide your full postcode then access to the additional information is restricted. This means that your full postcode information will be accessible only by the regional service(s) with whom the arrangement has been agreed.
 - Some information from NDTMS is sent by the NTA to the government, so that they can monitor the progress of the national drug and alcohol strategies. However, by the time the NTA submit reports from the NDTMS to the government, it is always in the form of total numbers of people and there is nothing in the information that could be used to identify you.
 - The NTA does not pass any identifiable information held on the NDTMS to the police or criminal justice agencies.
 - Your information is held on the NDTMS for at least 8 years.
 - Data from NDTMS is not placed on any register of addicts – no central register exists.
 - Your information is very useful for helping to plan and develop services that can best meet your needs. However, if you do not want information about you to be passed on, you have a right to say this.
 - If you wish to know more about the NDTMS (including why information is needed for the NDTMS, how information is handled within NDTMS and/or the type of information collected for NDTMS and the time it is retained) please ask your key worker.
-