



Public Health
England

Protecting and improving the nation's health

National drug and alcohol treatment monitoring system

Consent and confidentiality guidance

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: [@PHE_uk](https://twitter.com/PHE_uk)
Facebook: www.facebook.com/PublicHealthEngland

Prepared by: Jill Smith.

For queries relating to this document, please contact: jill.smith@phe.gov.uk



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Executive summary

Public Health England's (PHE) National Drug and alcohol Treatment Monitoring System (NDTMS) is the data collection system for the drug and alcohol treatment sector. It collects activity data from around 1,000 drug and alcohol treatment services in England, from within the community and the secure estate and for people of all ages. The data is used to monitor the progress of local treatment systems, and to assure the delivery of the treatment element of the Government's drug and alcohol strategies.¹

NDTMS is managed by PHE whose role is to protect and improve the nation's health and wellbeing, and reduce health inequalities. PHE is an operationally autonomous executive agency of the Department of Health (DoH). We are not part of the NHS but work closely alongside it.

You can find information on what PHE does at:

www.gov.uk/government/organisations/public-health-england

You can find details here on the range of information we use:

www.gov.uk/government/organisations/public-health-england/about/personal-information-charter

This document is designed to assist treatment services to understand and deal with concerns about patient confidentiality and data sharing with NDTMS. The NDTMS patient information leaflet and consent form must be used separately to provide information to service users about why some of their information is needed by NDTMS and to gain informed consent to permit the sharing of this data. This leaflet and consent form can be downloaded from: www.gov.uk/government/publications/confidentiality-guidance-for-drug-and-alcohol-treatment-providers-and-clients

¹ Drug strategy 2017 - GOV.UK; Alcohol strategy - GOV.UK

What information NDTMS uses and why

PHE is responsible for monitoring drug and alcohol treatment services across England.

NDTMS collects some personal information about the people using these services, including their initials, date of birth, gender, local authority area of residence, and the first part of their postcode.

NDTMS never collects full names and addresses. It never contacts service users, and it does not pass any personal information on to the police or any other organisation.

The information collected on the number of service users, the types of substances they use, the treatment they receive, and the outcomes they achieve is used to:

- monitor how effective drug and alcohol treatment services are
- support the improvement of outcomes for service users
- help plan and develop services that best meet local needs
- produce statistics and support research to inform policy decisions

PHE and NDTMS never publish any information that could be used to directly identify individual users of drug and alcohol treatment services.

Legal basis for NDTMS

NDTMS has a legal basis for collecting this personal data under General Data Protection Regulations (GDPR) of Article 6(1)(e) “*processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller*” and Article 9(2)(i) “*processing is necessary for reasons of public interest in the area of public health, such as or ensuring high standards of quality and safety of health care*”² but will continue with a policy of allowing service users to consent and to withdraw their consent for contributing their information to NDTMS, following the requirements of the common law duty of confidentiality.

² ico.org.uk/media/about-the-ico/disclosure-log/2014536/irq0680151-disclosure.pdf

Treatment service confidentiality

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 service user confidentiality. There is guidance available on the NHS Digital website³ that addresses confidentiality issues and which voluntary and private drug and alcohol treatment services may also find useful to inform their own policies.

All drug and alcohol treatment services are expected to have their own clear confidentiality/data handling policy which is understood by all members of staff; which is presented and clearly explained to the service user both verbally and in written form, before assessment for treatment begins. It should be explained on the service user's first visit and 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 is deemed to have been 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.

However the treatment service chooses to present their policy, the service users **MUST** be given the content of the **NDTMS patient information leaflet** and **ACTIVELY AGREE** to the sharing of some of their treatment data with NDTMS.

Appendix 1 provides an example of the minimum information a treatment service should provide to a service user about the service. It also includes the statement of consent which every service user **MUST** agree to before the service shares their data with PHE.

³ digital.nhs.uk/article/1200/Confidentiality

Sharing treatment data with 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 PHE the following should provide some guidance:

- a service user's initials, date of birth, gender and partial postcode are used by NDTMS. Although not fully identifiable data, these items of information still make it necessary to obtain explicit consent from the service user before collecting data to send to NDTMS
- explicit consent can be given orally (and documented in case notes) or in writing. It should be given freely in circumstances where the service user has been appropriately informed. There should be an understanding of available options and any concerns and queries should be addressed
- ideally, this consent would be part of the process of obtaining consent in general, when explaining local data collection policies
- the service user **MUST** be given the content of the **NDTMS patient information leaflet**, alongside the treatment service's confidentiality policy/leaflet, which explains what the information will be used for
- if the service user refuses consent, this should be recorded in the service users' case notes and clinical information system
- if a treatment service has not previously provided data to NDTMS but begins to do so for the first time, the service should seek retrospective consent from any existing service user to include previous episodes of treatment at the service or not provide those episodes to NDTMS
- where consent cannot be obtained, then mark the record as 'no consent' in the service users' case notes and clinical information system

Most service users are reassured when they know why their data is collected and how it is shared. It is necessary for treatment service staff to be aware of the reasons for collecting various data items and how information is used within your service. So that your service users are fully enabled to make an informed decision about sharing some of their personal and treatment data with NDTMS.

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 (eg treatment system partners) to make use of jointly procured software. This may necessitate information sharing across treatment services and/or drug and alcohol commissioners. 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 service user data if there is more than one service simultaneously providing treatment, irrespective of the treatment system or the software used. This is relevant, for example, 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.

PHE has introduced a data sharing agreement for all treatment services providing NDTMS data. If identifiable patient data is to be shared more widely than with PHE (eg with local authority Health and Wellbeing Board staff), services should ensure that appropriate consent and data sharing agreements are in place, as this is the responsibility of the treatment service that is collecting and sharing 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 (see How information is handled within NDTMS, p.9). In turn, this information should be passed on to service users who should feel reassured about the confidential nature of the data collection and sharing processes.

If your service does not already have data sharing protocols in place, there is helpful guidance on the Information Commissioners Office website⁴.

Why information is needed for NDTMS

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

- evaluate the efficiency and effectiveness of drug and alcohol treatment provision in delivering treatment outcomes for service users
- monitor the use of resources. This helps ensure equitable funding of drug and alcohol treatment services nationally
- provide a local picture of drug and alcohol users and their needs, which will assist service commissioners, Health and Wellbeing Boards and local

⁴ ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf

authorities in planning and developing better drug and alcohol treatment services that are more appropriate to their local area

- monitor the effectiveness of the government drug and alcohol strategies
- produce statistics and to support research on drug and alcohol use, treatment or general public health to help inform future policy decisions

How information is handled within NDTMS

Treatment service staff should become familiar with the information below and share its detail with service users who wish to have more information about PHE and the way in which they handle and use data:

- PHE is an Executive Agency of the Department of Health (DoH)
- the information required is passed monthly to NDTMS teams working in regional PHE offices. It may go via a third party (eg service commissioners). However, this document does 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 service users have attended more than one service. For this purpose, the initials, date of birth, gender, partial postcode and local authority of residence are recorded in NDTMS. These data items are stored on a database in a secure environment
- care is taken at all PHE locations 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
- any information published by the DoH or PHE is always in the terms of total numbers of people
- any research that would involve the use of data would be closely scrutinised by PHE and, where appropriate, research proposals would also have to obtain ethical approval
- data is matched from NDTMS by PHE with other government datasets to produce statistics which help evaluate the success of treatment programmes. All data matching is conducted by PHE and at no point is any identifiable information about service users passed onto other government departments. Data-sets that are used in this way include (but are not necessarily limited to):
 - Police National Computer and prison database
 - Department of Work and Pensions
 - Other routine health data-sets (eg Hospital Episode Statistics)
- under no circumstances is potentially identifiable data made public or provided to other government departments or the police
- data is not placed on any register of addicts – no central register exists

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

It is important that drug and alcohol treatment services offer the right treatment at the right time. It is also essential that treatment meets the different needs of the various local populations. For this reason, PHE seeks a range of data items. These include the dates of referral, treatment start and discharge. Alongside this, information is gathered on the type of treatments offered, the outcomes of treatment and the main and secondary problem substances used. PHE also need to know about the demographics of service users including gender and ethnicity to monitor inequality in service provision.

The information helps PHE and/or those who commission services, to use resources more appropriately to improve the effectiveness and quality of drug and alcohol treatment throughout the country. More detailed information about the NDTMS dataset can be found at: [Alcohol and drug misuse treatment core dataset collection guidance - GOV.UK](#)

NDTMS will hold service user information for different lengths of time depending on its purpose and use:

- regional NDTMS teams assist treatment services with data quality work and with understanding published reports on the data. The data they hold for these purposes is retained under a schedule in line with the NDTMS reporting period⁵ for a minimum of 29 months and a maximum of 41 months
- data collected using PHE's data entry tool is generally retained for a period of at least 8 years, but less if the treatment service closes or more if the treatment service remains open and has a justifiable reason for doing so such as avoiding duplication of service user information
- the national NDTMS collection is a valuable public health asset and is not deleted as there are ongoing requirements for its use as listed above eg trends analysis

⁵ **Reporting Time Frame:** This commences on 1 January in year 1 and then continues until 31 August in year 3. On 1 September year 3, the time frame is reset to commence on 1 January in year 2. Therefore, in May 2018, the time frame is from 1 January 2016 until current date and will change to commencing 1 January 2017 on 1 September 2018.

What if a service user wants to withdraw their data from NDTMS?

A service user may wish to remove some or all of their data from their current treatment provider or from other treatment providers. The actions required for this are explained in full in Appendix 2 but are the responsibility of the current or previous treatment provider. Where a treatment provider is no longer in existence, as the service user cannot be properly identified in the national collection it is not possible for NDTMS to remove the data as it is difficult to identify the data for a specific service user. As there is only a probabilistic match based on the original partially identifying information provided to those agencies of partial identifiers of the initials, date of birth, gender, partial postcode and local authority of residence rather than a full match based on agency level system generated client IDs.

Appendix 1

This information in section 1 is provided for your convenience and can be adapted, as necessary, by the treatment service. The information in 2 below must be imparted to service users either in its current format, or included word-for-word as part of your own service information sheets given to service users.

1. Information services should provide to service users

- we, your treatment service, ask you for information so that you can receive proper care and treatment. We collect your treatment data in an electronic system. If you consent, some of this treatment information will be provided to PHE's NDTMS using this system or in an electronic system provided for this purpose by PHE
- 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 treatment
- 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 NDTMS. This is the database used to collect information on drug and alcohol treatment provision. It is managed nationally by Public Health England, the body responsible for collecting drug and alcohol data and for overseeing drug and alcohol treatment in England.

2. Consent to NDTMS – service user agreement (see overleaf)

This information is also available as a printable document on:

www.gov.uk/government/publications/confidentiality-guidance-for-drug-and-alcohol-treatment-providers-and-clients

Consent to PHE NDTMS

The following words are to be used by all treatment providers in written or oral form for the purposes of gathering consent from individual clients to share some treatment data with Public Health England (PHE).

What NDTMS is and does: NDTMS is the National Drug and alcohol Treatment Monitoring System (NDTMS). It is used by PHE to collect information about drug and alcohol treatment in England. If you consent, your treatment service will share some of your treatment information with NDTMS.

What information NDTMS uses and why: PHE collects some personal information about people in treatment including your initials, date of birth, gender, the local authority area in which they live and the first part of your postcode. This reduces the risk of you being counted twice. This information is only shared with PHE if the people using treatment services agree and PHE never contact service users:

- your full name and address are NOT passed on to PHE
- no identifiable information held on NDTMS is passed on to the police or any other organisation
- your information is held on NDTMS to support ongoing trend and other research analysis⁶

The information is used to understand how many people are using these treatment services, how good the services are at helping people with substance misuse issues, to help improve them and produce statistics and research about drug and alcohol use and treatment. PHE never publish NDTMS information that could be used to identify individuals.

How NDTMS will protect your information: the security of the data you provide to NDTMS is of utmost importance and PHE staff are bound by law to protect the confidentiality of the information they collect and use. The personal information held is kept to a minimum and PHE makes sure that staff can only see the information that is required to do their job.

Sharing and linkage of NDTMS information: some information from NDTMS is cross referenced with data from other government departments and reports are sent back to them so that they can monitor the effectiveness of the national drug and alcohol strategies. Any data matching with other government departments is undertaken by PHE and at no point is your personal information, shared with the police or any other organisation. In addition, sometimes you may be seen by more than one agency and to

⁶ www.gov.uk/government/publications/confidentiality-guidance-for-drug-and-alcohol-treatment-providers-and-clients

assist with treatment outcomes profiles (TOP), NDTMS may share TOP information about you between the agencies from which you may have received treatment.

Withdrawal of consent: if you do not want information about you to be passed on to NDTMS then you have the right to say this and/or ask for your treatment information at your current service to be removed. This will not have any impact on the treatment you receive. You can ask your service or your keyworker for a copy of the NDTMS patient information leaflet for more information.

I consent to share my data with PHE NDTMS for the purposes set out above.

Service user name:

Service user signature:

Date:

Appendix 2

Withdrawal of consent

If a service user asks their service key worker to withdraw their data from NDTMS, the keyworker can take the following action at their service or provide the following information as appropriate. Also, your NDTMS regional team will be able to provide any further advice required.

A service user wishes to withdraw consent to sharing with NDTMS just from *this* episode at this agency

This is a simple task for the agency keyworker or administrator: change the NDTMS consent field from Yes to No in the current open episode. This will take effect at the time the agency next loads a file into NDTMS.

(Information for agency NDTMS administrator: When agency next loads a file into NDTMS, the episode level information will be removed from national collection. Agency sees activity as a mismatch but is already 'resolved' by the system).

A service user wishes to withdraw consent to sharing with NDTMS from *all* episodes at this agency

Agency uses Data Entry Tool system to provide NDTMS data:

This can be completed by the agency keyworker or administrator: change the NDTMS consent field from Yes to No in each open or closed episode at the agency

[Information for agency NDTMS administrator: When agency next transfers a file, the client ID field will be used to identify persisted data in national collection for this service user in this agency and all information for all episodes for this client ID will be removed from national collection leaving only Agency code, client ID and consent field in the records. The agency will see the activity as mismatches, but they are already 'resolved' by the system]

NB: if the agency accidentally 'misses' a change to an episode which is in reporting timeframe¹, then that missed episode will remain as a consented to record. If the 'missed episode' is before the reporting timeframe, then that will also be assumed by NDTMS as being non-consented to simply based on client ID and NDTMS will remove data from all episodes for this service user at this agency not in the loaded file.

Agency uses casefile management system to provide NDTMS data:

The agency keyworker or administrator should edit all episodes (reopening closed ones if necessary), changing the NDTMS Consent field from Yes to No

[Information for agency NDTMS administrator: When the agency next loads a reporting

extract file or a full extract, client ID will be used to identify persisted data in national collection for this service user in this agency and all information for all episodes for this client ID will be removed from national collection leaving only Agency code, client ID and Consent field in the records. The agency will see the activity as mismatches, but they are already 'resolved' by the system]

NB: if the agency accidentally 'misses' a change to an episode which is in the reporting timeframe, then that missed episode will remain as a consented to record. If the 'missed episode' is before the reporting timeframe and it is a reporting extract file, then that will also be assumed by NDTMS as being non-consented to simply based on client ID and will remove data from all episodes not in the loaded file (which will normally be pre-reporting period timeframe files). If the missing episode is in a full extract file, then NDTMS will assume the consent field is correct and keep that episode's full information.

A service user wishes to withdraw consent to sharing with NDTMS from episodes at other agencies

In this case, the service user must approach the other agencies and ask for the data to be removed by them as explained above. If the agencies are no longer in existence, then NDTMS cannot remove the data as the individual cannot be properly identified in the national collection as there is only a probabilistic match based on the original partially identifying information provided to those agencies of initials, date of birth, gender, partial postcode and local authority of residence rather than a full match based on agency level, system generated client IDs.

ⁱ **Reporting Time Frame:** This commences on 1 January in year 1 and then continues until 31 August in year 3. On 1 September year 3, the time frame is reset to commence on 1 January in year 2. Therefore, in May 2018, the time frame is from 1 January 2016 until current date and will change to commencing 1 January 2017 on 1 September 2018.