



Public Health
England

Protecting and improving the nation's health

Data sharing protocol

Protocol between drug and alcohol treatment services and Public Health England for the routine supply of data to the National Drug and alcohol Treatment Monitoring System

August 2018

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. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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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 and Social Care (DHSC). 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 providing data to NDTMS to understand and deal with concerns about patient confidentiality and data sharing with NDTMS.

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

Scope

This overarching protocol sets out the principles for information-sharing between drug and alcohol treatment services (the data providers) and PHE. It sets out the conditions that all people working for or with the data providers must follow when sharing information with PHE and how PHE will hold and use that data securely and as declared.

Aims

The aim of this protocol is to facilitate the lawful sharing of personal data between data providers and NDTMS and to provide a framework to:

- increase awareness and understanding of the key issues
- identify the legal basis for sharing service-user information with PHE
- protect the data providers and PHE from accusations of wrongful use or sharing of service-user data.
- declare the purposes for the use of the data shared with PHE

By submitting data to NDTMS, data providers are making a commitment to adhere to or demonstrate a commitment to achieving the appropriate compliance with the Regulation (EU) 2016/679 General Data Protection Regulation (GDPR) as enacted in England and Wales under the Data Protection Act 2018.

Data providers are expected to promote staff awareness of the process requirements of sharing service-user information with PHE. This will be supported by the production of appropriate guidelines by PHE and made available directly to data providers and also on the GOV.UK website.

In agreeing to submit data to NDTMS, the data providers undertake to meet the requirements of this protocol until such time as they choose to cease to do so or are no longer able to through changing local contractual arrangements.

The legal framework

Permission to process (lawful use of the data)

PHE is an executive agency of the Department of Health. Its function is to fulfil the Secretary of State for Health's statutory duties to protect and improve the health of the population of England as set out in Sections 2A and 2B of the NHS Act 2006, as inserted by the Health and Social Care Act 2012.

PHE has a legal basis for collecting drug and alcohol treatment data under 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"
- 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"

To comply with the requirements of the common-law duty of confidentiality and within the requirements for Article 8(1) of the Human Rights Act 1998, service users will be allowed to consent and to withdraw their consent for contributing some of their treatment information to NDTMS.

The data provider will therefore undertake to:

- use the NDTMS consent and confidentiality guidelines to ensure that their staff and service users are made aware of the data NDTMS collects and the purposes that data is used for, and that service users have consented to their data being shared with PHE. PHE has provided a NDTMS consent and confidentiality guidance document and NDTMS patient information leaflet. These documents can all be found at www.gov.uk/government/publications/confidentiality-guidance-for-drug-and-alcohol-treatment-providers-and-clients
- make the NDTMS patient information leaflet available to all their service users, for example by display in their treatment premises, on notice boards and/or on request, for the purposes of ensuring service users are aware of their rights under the GDPR. (For young people, the data provider will undertake to assess their competency to give consent and will seek parental or guardian permission to do so if necessary.)

Breaches by the data provider of these 2 conditions will be a material breach of this protocol.

The data provider will gather informed consent using the NDTMS consent statement from a service user for sharing data with PHE. This can be given by the service user orally or in writing. It will be given freely in circumstances where the service user has been appropriately informed. The service user will understand the available options and any concerns and queries will be addressed before the data provider enters 'YES' into the NDTMS consent field in their case notes and clinical system.

If the service user declines to give their consent then this will be recorded in the Data Provider's case notes and clinical system by entering 'NO' into the NDTMS Consent field and NDTMS will filter out (not accept) that data subject's information and not collect that data for such service users.

Data providers must be aware that a service user may withdraw consent to sharing their data with NDTMS. In this case the data provider should ensure the service user's records reflect their requirements for the current and previous episodes at their service. Appendix 1 provides more details on how withdrawal of consent to sharing data with NDTMS is managed by a data provider.

If a data provider has not previously provided data to NDTMS but begins to do so for the first time, then they 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.

The data controller for NDTMS is Professor John Newton, PHE Senior Information Risk Owner (SIRO), Health Improvement Directorate. PHE will assume the responsibility of data controller for all data once transferred to it from the data provider.

Information covered by this protocol

The information covered by this protocol is both personal data and special category data as defined in the GDPR. The data collected by NDTMS is partially identifying information including initials, date of birth, sex, the local authority area in which service users live and the first part of their postcode. The data items and potential responses are declared in the NDTMS reference data document which can be found at:

www.gov.uk/government/publications/national-drug-treatment-monitoring-system-reference-data.

Purpose for the use of NDTMS data

The National Drug and alcohol Treatment Monitoring System (NDTMS) records those people attending services for drug and alcohol treatment across the whole of England.

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 (this helps ensure equitable funding of drug and alcohol treatment services nationally)
- support and evaluate 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
- monitor the effectiveness of the government drug and alcohol strategies.

PHE never publishes any NDTMS information that could be used to directly identify individual users of drug and alcohol treatment services. NDTMS only publishes anonymised aggregate data and these reports can be found on www.ndtms.net or www.gov.uk/government/collections/alcohol-and-drug-misuse-prevention-and-treatment-guidance.

Data release and publishing

PHE will be permitted to use the data for the purpose of carrying out analysis using appropriate statistical methods and the output of such analysis may be published by PHE on its website and in peer-reviewed journals. PHE will only publish drug and alcohol treatment data 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 that 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.

Breaches

The data provider originally submitting the information will be notified by PHE immediately of any breach of confidentiality or incident involving a risk or breach of the security of information.

Retention, storage and disposal of NDTMS data

Once submitted to NDTMS, PHE will retain the service user data for the purposes outlined above and including for trend analysis and research purposes.

The data will be stored by PHE in accordance with its standard security policy for storage of confidential data and the processes and policies of the Data Security and Protection Toolkit. NDTMS is a secure system with 2-factor authenticated, restricted access to a discrete set of predefined users and sub-systems.

PHE will comply with any reasonable request from a data provider requiring PHE to amend, transfer or delete the service user data submitted to NDTMS.

Confidentiality

PHE formally acknowledges its explicit commitment to maintaining the confidentiality, safety, security and integrity of treatment data provided under this protocol and which may be held under its guardianship. PHE will ensure this is achieved in accordance with NHS best practice and the procedures of the Data Security and Protection Toolkit².

PHE is committed to ensuring that all processing of and exchanges of data comply with: the legal framework for data protection and confidentiality; the updated Caldicott principles and the information governance assurance framework for health and care organisations codified in the Data Security and Protection Toolkit managed by NHS Digital (formerly the Health and Social Care Information Centre). All data processing and storage will be within the UK.

As users of the data supplied, PHE are obliged to comply with all applicable data protection laws. PHE will take reasonable steps to ensure the reliability of all its employees who have access to NDTMS. PHE will ensure that their staff know, understand and guarantee to maintain the confidentiality requirements of each of their statistical resources and will ensure that anyone involved with the processing of the statistical resource is aware of the penalties of wrongful disclosure.

² <https://digital.nhs.uk/data-and-information/looking-after-information/data-security-and-information-governance/data-security-and-protection-toolkit>

PHE staff will only be given access to personal data where there is a legal right, in order for them to perform their duties in connection with the services they deliver.

Both PHE and data providers are responsible for ensuring every member of their staff is aware and complies with the obligation to protect confidentiality and a duty to disclose information only to those who have a right to see it.

Both PHE and data providers will ensure that any of its staff accessing the NDTMS data is trained and fully aware of their responsibilities to maintain the security and confidentiality of personal information.

All drug and alcohol treatment services submitting data to NDTMS are expected to have their own clear confidentiality or 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.

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 before their data is submitted to NDTMS.

Individual responsibility

All staff working for PHE or the data providers have a responsibility to keep personal information secure from unauthorised disclosure. Staff need to be clear:

- what information can be shared and under what circumstances
- what information cannot be shared and under what circumstances
- who to go to for advice if they are not sure what to do

Appendix 1 - 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. Their 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. The agency keyworker or administrator changes 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. The agency keyworker or administrator changes 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 timeframe³, 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.

³ 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.

- 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 *all* episodes in reporting time framework at other agencies
- a service user wishes to withdraw consent to sharing with NDTMS from *all* episodes at other agencies

In these last 2 cases, 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 client IDs.