



Public Health  
England

Protecting and improving the nation's health

# HIV and AIDS Reporting System: Implementation Guidance

Version 1.0/ October 2016

## 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-class 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 are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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This information standard (SCCI1570) has been approved for publication by the Department of Health under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Standardisation Committee for Care Information (SCCI), a sub-group of the National Information Board.

This information standard comprises the following documents:

- Requirement Specification
- Change Specification
- Implementation Guidance.

An Information Standards Notice (SCCI1570 Amd 20/2015) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (eg paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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# Glossary

Term	Acronym	Definition
Acquired Immune Deficiency Syndrome	AIDS	Acquired immune deficiency syndrome is a disease of the human immune system caused by HIV.
Antiretroviral therapy	ART/ARV	The combination of several antiretroviral medicines used to slow the rate at which HIV makes copies of itself (multiplies) in the body.
British Association for Sexual Health and HIV	BASHH	UK professional association representing professionals involved in sexual health care. It acts as a national advisory body to professions and other organisations on all aspects of sexual health.
British HIV Association	BHIVA	UK professional association representing professionals involved in HIV care. It acts as a national advisory body to professions and other organisations on all aspects of HIV care.
Genito-urinary Medicine	GUM	This is a specialised service, whose primary function is the provision of screening, diagnosis and management of sexually transmissible infections and related genital medical conditions.
Genito-urinary Medicine Clinical Activity Dataset	GUMCAD	Dataset for case-based disaggregate surveillance system used to monitor the number of sexually transmitted infections in England, Wales and Northern Ireland.
Health Protection Agency	HPA	The HPA was a non-departmental public body whose remit is to provide an integrated approach to protecting UK public health through the provision of support and advice to the NHS, local authorities, emergency services, other Arms Length Bodies, the Department of Health and the Devolved Administrations. The HPA transferred to Public Health England in 2013.
HIV and AIDS reporting system	HARS	The name of the new HIV dataset.
Human Immunodeficiency Virus	HIV	The virus that causes AIDS.
National Reference Group	NRG	The group overseeing the development of the HARS standard and its implementation.
National Tariff Payment System	NTPS	Supersedes Payment by Results.
Patient identifiable information	PII	Information collected for surveillance that is sensitive.
Payment by Results	PbR	A rules-based system for paying health care trusts. Payment is linked to activity and adjusted for casemix.

		Superseded by NTPS.
Public Health England	PHE	The successor public organisation into which the HPA was integrated in 2013.
Public Health Laboratory Service	PHLS	The predecessor to the HPA and PHE.
Recent Infection Testing Algorithm	RITA	An algorithm reliant on results of a test of recent infection on newly diagnosed persons with epidemiological and clinical information to allocate patients as being either recent or non-recent HIV infections with HIV.
Sexually Transmitted Infection	STI	An infection that is transmitted sexually.
Survey of Prevalent HIV Infections Diagnosed	SOPHID	An annual census of people living with a diagnosed HIV infection. This survey has been conducted since the mid-1990s. SOPHID is in the process of being amalgamated with the new HARS dataset.
Viral load	VL	Viral load is the term used to describe the amount of HIV in the patient's blood. The higher the viral load, the faster the CD4 cell count will fall, and the greater the risk of becoming ill due to HIV. The result of a viral load test is described as the number of 'copies' of HIV's genetic material (RNA) per millilitre (copies/ml).

## Aim of document

This document aims to provide guidance to support the implementation of the updated HIV and AIDS Reporting System (HARS) dataset to both new (see Section 2) and existing users of HARS (see Section 3) as set out in SCCI1570 HIV and AIDS Reporting System.

This standard covers all HIV care providers (data submitters, approximately 180 sites) in England covered by the NHS.

## Scope of document

This document provides guidance on how to implement the HARS dataset either as a new user or as an existing users looking to make changes resulting from the release of the updated HARS Information Standards Notice (ISN). This document should be read together with the following documents:

1. HARS Requirement Specification
2. HARS Change Specification
3. HARS User Guidance
4. NHS Data Model and Dictionary Change Request.

## Out of scope of this document

Detailed justification for the development of the information standard is out of scope of this document.

## Supporting documents

A set of documentation has been developed to support the HARS Information Standard. A breakdown of the individual products can be found below:

Document	Description	Location
Information Standards Notice	Notification of publication of a new or amended standard.	SCCI webpage
Change Specification	Outlines a list of the limited changes made to HARS since the initial standard was approved in 2012. For example, the addition of new data items the renaming of data items/tables to conform to NHS Data Model & Dictionary and the deletion of	SCCI webpage

	other items.	
Requirement Specification	Outlines the scope of the Information Standard and how it should be implemented. Provides an overview of the requirements for both care providers and system suppliers, and associated conformance criteria (the tests that can be measured to assess whether the standard is being used correctly).	SCCI webpage
NHS Data Model and Dictionary Change Request	Provides a detailed technical specification of all changes made to the NHS Data Model and Dictionary as a result of the changes to this information standard.	SCCI webpage
Data Dictionary	Detailed overview of every data item in the dataset.	HARS webpage
User Guidance	Guidance for providers about the content of the data set, including behavioural guidance about interpreting each data item and the submission process.	HARS webpage
Technical Guidance	Guidance for providers and system suppliers about the structure and content of the output XML file, including guidance about how to map/format each individual data item and explanation of messages received from the system.	HARS webpage

SCCI webpage: <http://content.digital.nhs.uk/isce/publication/scci1570>

HARS webpage: <https://www.gov.uk/guidance/hiv-surveillance-systems>

## New users to the standard

### Background

The HIV and AIDS Reporting System (HARS) is a national data system developed by the Health Protection Agency (HPA) in 2012. The HPA was incorporated into Public Health England (PHE) in 2013, who have since overseen the rollout and implementation of the dataset.

HARS is designed to capture information about patients at their HIV diagnosis, and for each subsequent attendance at an HIV outpatient clinic for the remainder of their care. The primary aim of HARS is to collect data for public health surveillance. Such data are critical in informing the public health response to HIV and the implementation and evaluation of HIV prevention initiatives.

HARS has two secondary aims:

- HARS will monitor the access of HIV patients to HIV care and the quality of care HIV patients will receive
- HARS will be used to directly inform the commissioning of services via the national HIV outpatient tariff

The data flow through a secure web portal which performs automated validations and the database is managed by the HIV and AIDS Reporting Section in PHE.

After undergoing further cleaning and de-duplication, summaries of the data are published on the .GOV webpage<sup>1</sup> on an annual basis.

On a quarterly basis, anonymised and aggregated data will be provided to NHS England to support the national tariff payment system.

### General

As a new user to HARS, it is important to work with PHE and your organisation's IT system supplier to ensure that the data upload is efficient, robust and secure. New users also need to be aware of the new developments outlined on page 12.

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<sup>1</sup> <https://www.gov.uk/government/statistics/hiv-annual-data-tables>

A user account on the secure HIV and STI web portal, which is used for the upload and validations of the HARS submission, will be required and can be requested by emailing [HARSQueries@phe.gov.uk](mailto:HARSQueries@phe.gov.uk).

### Implementation checklist for new users

Task	Description
1. Understand the background and the scope of the Information Standard	Review this <i>Implementation Guidance</i> along with the <i>Requirement Specification</i> to fully understand the background, objectives and scope to this Information Standard.
2. Understand the data items being requested	Review the <i>Data Dictionary</i> and the <i>User Guidance</i> to understand at a higher level the data items requested.
3. Understand the key implementation and submission dates for this standard	The <i>Information Standards Notice</i> outlines the key implementation and conformance dates for this standard. The <i>User Guidance</i> document outlines the key submission dates for this standard on an ongoing basis.
4. Decide whether and how data items will be collected	Look more closely at each individual data item in the <i>Data Dictionary</i> and check whether local systems record the data in a way that means it can be submitted to HARS. Read the <i>User Guidance</i> for further guidance on the interpretation of the data items.
5. Consider impact of collecting and reporting HARS data	Read this <i>Implementation Guide</i> and the <i>User Guidance</i> to assess the impact of HARS in terms of workload, training, business processing and data security. Consider the current state of readiness.
6. Ensure the organisation complies with Information Governance requirements	The <i>User Guidance</i> signposts information relating to Information Governance (IG) issues around the handling and submission of HARS data.
7. Understand data submission and validation process	Review the <i>Technical Guidance</i> to fully understand the XML data structure and the <i>User Guidance</i> for the submission process to the HIV and STI Web Portal.
8. Consider any hardware/software requirements to implement the standard	There are a number of commercial system suppliers with HARS compliant software and these systems are how the majority of HARS data is reported.  If local systems are to be used, considerations will have to be made regarding the software and hardware and where the database will be held.
9. Obtain HIV and STI Web Portal login credentials	The HIV and STI Web Portal ensures secure transfer of confidential patient data between providers and PHE. The portal also runs automated validations for HARS reports ensuring instant feedback on data quality.  Detailed instructions are available in the <i>User Guidance</i> on how to contact PHE for a login and how to submit the report on the Web Portal.

<p>10. Construct HARS data extract</p>	<p>The Information Standard does not stipulate any particular processes that should be used to generate the required output file. In the majority of cases a commercial system supplier will provide the function to collect and report HARS data in the required XML format.</p> <p>The <i>User Guidance</i> document provides further support on the submission process and the <i>Technical Guidance</i> defines the exact structure and content of the XML submission file.</p>
<p>11. Fully understand the validation reports provided</p>	<p>The <i>Technical Guidance</i> defines the structure that the reports should conform to. On upload of the file the file will be validated against the XML schema for formatting. Any errors must be corrected.</p> <p>Once the XML schema validation is passed the data is validated against a list of business rules ensuring high data quality. The validations along with further detail on the validation process can be found in the <i>User Guidance</i> document.</p>
<p>12. Submit a test file to the HIV and STI Web Portal</p>	<p>Ensure data is being collected and reported correctly by submitting a test file to the Web Portal. This process also facilitates familiarisation with the validation process and ensures data issues are raised at an early stage.</p>

## Existing users to the standard

### General

As an existing user to HARS, it is important to be aware of the changes, the responsibilities and requirements to implement the changes, and the timescales involved. The Implementation checklist below outlines tasks which should be considered to support implementation of the dataset.

Changes to the central database and automated validation function on the HIV and STI web portal will be implemented and managed by PHE.

### Details of changes

The details of the changes to HARS are summarised in the HARS Data Dictionary. The changes are categorised into 3 groups:

- new data items: seven new data items have been introduced (only two of which are mandatory)
- changes to coding: 13 data items have had coding changes
- retired data items: two data items have been retired from the dataset (Gender at birth and Clinical Trial Indicator).

The changes have been implemented to address changes in HIV care and management which is a fast moving field as well as to support commissioning of HIV services. Specifically, the benefits of these changes are:

- improved data to support commissioning of HIV services
- move to national standard of coding of ART and AIDS defining illnesses ensuring new codes are added in a timely fashion
- corrections in light of developments in HIV testing and care management

There are no changes to the flow of data and the submission process remains the same.

## Implementation checklist for existing users

Both new and existing users should consider the following list:

Task	Description
1. Understand the background of the changes to the Information Standard	Review this <i>Implementation Guidance</i> along with the <i>Requirement Specification</i> and <i>Change Specification</i> to fully understand the background, objectives and scope to this Information Standard.
2. Understand how the new or amended data items are structured within the data set	Review the <i>Change Specification</i> , <i>Data Dictionary</i> and the <i>Technical Guidance</i> to understand how the new or amended data items are grouped, and how those groups relate to each other. The <i>User Guide</i> contains detailed information about each change made.
3. Decide whether and how new or amended data items will be collected	Look closely at each individual change in the <i>User Guide</i> and check whether local systems record the data in a way that means it can be submitted in accordance with the <i>Technical Guide</i> . Read the <i>User Guidance</i> for further guidance and interpretation of the changes to the standard.
4. Ensure the organisation complies with Information Governance requirements.	The changes introduced in this standard have no IG implication as there are no changes to patient identifiable information collected in the data set. There are also no changes to the high-level collection/processing principles. Existing users must ensure information governance requirements continue to be met.
5. Understand changes to the submission process	Review the <i>Technical Guidance</i> , to fully understand any changes to the data extract required. There have been no changes to the submission process itself however please review the <i>User Guidance</i> for information on additional validations introduced.
6. Construct data submission file	The Information Standard does not stipulate any particular local processes that should be used to generate the required XML output file. In most cases a commercial system supplier will provide software to collect and report HARS data. The <i>User Guidance</i> provides further support on the submission process and the <i>Technical Guidance</i> defines the exact structure and content of the submission file.
7. Fully understand the validation reports provided by the HIV and STI Web Portal	The <i>User Guidance</i> defines the reports that will be returned to data providers after upload and lists all the error and warning messages that may be produced. This specification should be reviewed to ensure a thorough understanding of the errors and warnings that may be produced for the new or amended data items and also how any issues can be fixed for later submissions.
8. Submit a test file to the HIV and STI Web Portal	Ensure data are being collected and reported correctly by submitting a test file to the Web Portal. This process also facilitates familiarisation with the validation process and ensures data issues are identified at an early stage.

## Timelines for changes

### Implementation period

The implementation period for the updated HARS dataset is from 1 November 2016 to 31 March 2017.

If the dataset has been implemented before 1 April, PHE will still be able to validate the files and provide feedback on data quality however the data may not flow into the central database.

### Conformance date

The conformance date for the updated dataset to be implemented in all HIV service providers in England is 31 March 2017.

Users who do not feel this is feasible are advised to contact PHE as soon as possible.

The previous version of the HARS dataset will continue to be accepted until all providers have transitioned to the updated HARS dataset.

# Guidance and support

## Guidance

The guidance documentation for the standard can be found on the PHE webpage:

<https://www.gov.uk/guidance/hiv-surveillance-systems>

The link to the HIV and STI web portal can be found at:

<https://hivstiwebportal.phe.org.uk/login.aspx>

In addition to the published documentation, a quarterly reporting protocol will be sent out to all providers to remind them of the reporting deadlines and to provide further guidance based on feedback received.

## Support mechanisms

Detailed guidance documents are provided and every effort has been made to make these as comprehensive as possible however it is acknowledged there may be queries outstanding given the complex nature of the data being captured. If this is the case please contact the HARS team at PHE on 020 8327 6827 or [HARSQueries@phe.gov.uk](mailto:HARSQueries@phe.gov.uk). Any queries raised will assist in the development of the guidance materials.

Technical questions relating to how the system extracts or processes data locally should be directed to the software supplier.

If there are issues with the use of the web portal to submit and validate the data, please email [HARSQueries@phe.gov.uk](mailto:HARSQueries@phe.gov.uk).