

Data Provision Notice

National Audit of Pulmonary Hypertension for Scotland

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Contents

Background	3
Purpose of the collection	3
Benefits of the collection	3
Legal basis for the collection, analysis, publication and dissemination	4
Persons consulted	5
Scope of the collection	5
Form of the collection	5
Manner of the collection	5
Period of the collection	6
Data quality	6

Background

The Health and Social Care Act 2012 (the 2012 Act) gives the Health and Social Care Information Centre, now known as **NHS Digital** and hereafter referred to by this name, statutory powers, under section 259(1)(b), to request data from any person where NHS Digital considers the data is necessary or expedient for it to have for the purposes of carrying out its functions under Part 9 Chapter 2 of the 2012 Act.

The data, as specified by NHS Digital in this published Data Provision Notice, is required to support a Non-Mandatory Request made under section 255 of the 2012 Act by NHS National Services Scotland to NHS Digital. Therefore, organisations that are in scope of the notice are requested, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose of the collection

The National Audit of Pulmonary Hypertension (NAPH) is a collection across pulmonary hypertension (PH) centres in England and Scotland. The purpose of this collection is to provide clinical teams with performance data on their own centres so that they can identify where improvements in the quality of care can be made for their patients. NHS Digital provides analytical services and creates the annual report and supplementary documentation. There is no dissemination of the data collected. The collection has been running for ten years (under a different legal basis) and the annual reports published have been able to demonstrate where PH centres have improved care for patients. The collection is directed in England by NHS England and NHS Services Scotland is making a Non-Mandatory Request for the collection and analysis of data from Scotland.

Benefits of the collection

Having clinically agreed standards enables the PH centres to benchmark their performance against other centres, to be able to demonstrate improvements in the level of care provided to patients and to assure patients of the quality of services being provided. Examples of where improvements have been made over the last 3-4 years across England and Scotland include:

- an increase in the number of new patients being seen or discharged within 30 days
- an increase in the number of patients receiving a timely diagnosis.

Examples where patients have been assured that the service provided by their PH centre has been consistently high include:

- patients receiving a PH drug should have had a PH diagnosis recorded
- patients receiving a PH drug should have an annual consultation.

Legal basis for the collection, analysis, publication and dissemination

NHS National Services Scotland (NSS) is a Special Health Board constituted on 1 April 1974 under the former National Health Service (Scotland) Act 1972 and now the National Health Service (Scotland) Act 1978 as amended (the 1978 Act).

Legal basis for collection and analysis

NHS NSS provides advice and services to NHS Scotland and the wider public sector and is accountable to the Scottish Government. Section 10 of the 1978 Act expressly permits NHS NSS to undertake activities on behalf of all or any of the Health Boards.

The Non-Mandatory Request made by NHS NSS under sections 255 and 256 of the 2012 Act provides the legal basis for NHS Digital to collect and analyse data from the Scottish pulmonary hypertension centre, Golden Jubilee National Hospital, Clydebank, for Scotland's continued participation in the NAPH.

NHS NSS has confirmed that they can request collection of this information by NHS Digital, because in accordance with section 256(2)(b) it is information that NHS NSS can lawfully require NHS Boards in Scotland to disclose to it under the 1978 Act.

A copy of the Request is published here: <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/nhs-scotland-non-mandatory-requests/national-audit-of-pulmonary-hypertension---national-services-scotland-non-mandatory-request>

The information to be collected is set out within the [NHS Digital Specification - NAPH Dataset 2020-21 v2.3 090620](#). NHS Digital will carry out analysis to establish the validity of the data; the analysis to be performed is documented in the National Audit of Pulmonary Hypertension for NHS Scotland Specification. NSS requests that NHS Digital carries out the collection and analysis in accordance with these Specifications or with any subsequent final versions of the same documents created by NHS Digital and agreed with NSS. The data from Scotland will not be linked with other NHS Digital assets.

Legal basis for publication and dissemination

In line with its statutory duty under section 260(1) of the 2012 Act, NHS Digital will analyse the information to publish an annual report.

Under section 261 of the 2012 Act, NHS Digital may disseminate the data to those that have been authorised via its Data Access Request Service (DARS) with oversight from the Independent Group Advising on the Release of Data (IGARD).

This information is required by NHS Digital under section 259(1)(b) of the Health and Social Care Act 2012.

In line with section 259(5) of the 2012 Act, all organisations in scope are requested to comply with the requirement and provide information to NHS Digital in the form, manner and period specified in this Data Provision Notice.

This Notice is issued in accordance with the procedure published as part of NHS Digital's duty under section 259(8).

Persons consulted

Following receipt of the Non-Mandatory Request to establish a system to collect and analyse information for the Data Provision Notice - National Audit of Pulmonary Hypertension for Scotland, NHS Digital has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- **The NAPH Pulmonary Hypertension Project Board**, which includes NHS Digital, NHS England and NHS Improvement, NHS Scotland, NHS Wales, Health and Social Care Service in Northern Ireland, paediatric PH services, Pulmonary Hypertension UK (PHA UK) patient group, the PH Clinical Reference Group, PH Physicians Group, specialist nurses and service managers.
- **NAPH User Group**, which is made up of physicians, data managers and other clinicians from the 8 PH centres in the UK.
- **Pulmonary Hypertension Outcomes Group**, which includes representation from all the 8 PH Centres, PHA UK and NHS England and NHS Improvement.

Scope of the collection

Under section 259(1)(b) of the Health and Social Care Act 2012, this Notice is served in accordance with the procedure published as part of the NHS Digital duty under section 259(8) on the following persons:

- The Golden Jubilee National Hospital, Clydebank

Under section 259(5) of the Health and Social Care Act 2012 the organisation specified in the above Scope is requested to comply with the Form, Manner and Period requirements below:

Form of the collection

The information to be collected is about patients.

- The data items to be collected are:
 - Date of Birth in the form of month, year and a default date of the first day of the birth month
 - Sex
 - Postal District
 - Pseudonymised CHI code (the CHI code is the patient identifier used in Scotland)
 - Information about Referral, Diagnosis, Treatment and Outcomes.

The specification for the NAPH further describes the information to be provided and can be found on the NHS Digital website at: <https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-pulmonary-hypertension-audit>

Manner of the collection

Data will be submitted by the Golden Jubilee National Hospital, Clydebank using the NHS Digital secure online Clinical Audit Platform (CAP). A link to the system is available here: <https://clinicalaudit.hscic.gov.uk/>

Staff submitting data to CAP will be required to register in order to use the system by creating a Single Sign On (SSO) account with NHS Digital and completing and submitting a registration form which needs to be signed off by the Caldicott Guardian of the provider organisation.

The registration form and operational guidance can be found under User Documents for each of the individual audit projects on the NHS Digital website <https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-pulmonary-hypertension-audit>

Period of the collection

This is a continuous collection. Data has been entered by Scotland since the start of the collection in 2009 – under a different legal basis.

Data quality

An extract is taken in March and May to produce data quality reports which are returned to the provider, a final extract is taken in June from which full analysis is undertaken to produce the annual report and supporting documents.

An annual report is published by NHS Digital in October each year.

For further information

www.digital.nhs.uk

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