

Data Provision Notice

For National Audit of Pulmonary Hypertension

Information Asset Owner: Chris Dew

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Background

The Health and Social Care Act 2012 (the 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), to require data from health or social care bodies, or organisations who provide health or adult social care in England, where it has been directed to establish an information system by the Department of Health (DH) (on behalf of the Secretary of State) or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice, is required to support a direction from NHS England to NHS Digital. Therefore, organisations that are in scope of the notice are legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

Purpose of the collection

NHS England has directed NHS Digital to establish and operate a system for the collection and analysis of information for the National Audit of Pulmonary Hypertension (NAPH).

The NAPH is funded by NHS England and delivered by NHS Digital.

The NAPH has been designed to deliver a reliable measurement system for pulmonary hypertension. The measurements include the basic structure of care services, the treatment of patients presenting with active disease and the outcomes.

The audit is a measurement system to support improvement in the quality of care of people in the care of the pulmonary hypertension services and seeks to address three key questions:

- Structures: Are pulmonary hypertension services appropriate?
- Processes: Are patients receiving the right treatment in a timely manner?
- Outcomes: What are the outcomes for patients with pulmonary hypertension?

The key findings of the audit (aggregate level) are published on a regular basis and are available on the NAPH website at <http://digital.nhs.uk/ph>

Benefits of the collection

The NAPH enables all pulmonary hypertension services to measure their performance against professionally agreed clinical guidelines and peer units.

Legal basis for the collection, analysis, publication and dissemination

NHS Digital has been directed by NHS England under section 254 of the Health and Social Care Act 2012; to establish and operate a system for the collection and analysis of the information specified for the NAPH in the Technical Output Specification version 1.8 or any subsequent amended version of the specification, as approved by the NAPH Project Board. The direction was accepted by the NHS Digital Board on 27 January 2016; the signed copy

is published on the gov.uk website <https://www.gov.uk/government/organisations/health-and-social-care-information-centre/about/our-governance>

The Technical Output Specification is available on the NHS Digital website www.digital.nhs.uk/ph

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

In line with section 259(5) of the Act, all pulmonary hypertension specialist services within NHS Trusts in England must 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 a Direction to establish and operate a system to collect information for the NAPH, NHS Digital has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- NHS England
- NHS Scotland
- NHS Wales
- UK Pulmonary Hypertension Physicians Group
- Clinicians
- Healthcare professionals
- Patient body representatives

Scope of the collection

Under section 259(1) 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) of the Act for all pulmonary hypertension services within NHS trusts in England.

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

Form of the collection

The following patient identifiable information is included in the collection:

- NHS Number
- Date of birth

- Surname and forename (for local identification only)
- Postcode

Full details of the data to be collected can be found in the NAPH Technical Output Specification under the “User Documents” section of the NAPH website <http://digital.nhs.uk/ph>

Manner of the collection

The NAPH is a continuous collection with data collected throughout the year. Pulmonary hypertension specialist services within NHS trusts should input data at any point throughout the year into the NAPH online data collection tool.

Data should be inputted into the online data collection tool throughout the year. Users must register for the online data collection tool and gain Caldicott Guardian approval.

Guidance on how to register is available under the “User documents” section of the NAPH website at <http://digital.nhs.uk/ph>

Period of the collection

The NAPH is a continuous collection with data collected and submitted throughout the year.

A cut of the data is taken on an annual basis, usually in June each year, with results fed back to participating units and published on a regular basis. Providers will be informed of the specific timescales each year.

Cut off dates for subsequent reports will be made available on the NAPH website at <http://digital.nhs.uk/ph>

Burden of the collection

Steps taken by NHS Digital to minimise the burden of collection

In seeking to minimise the burden it imposes on others, in line with sections 253(2)(a) and 265(3) of the Health and Social Care Act 2012, NHS Digital has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This assessment is carried out by the Data Standards and Assurance Service (DSAS) which carries out a Detailed Burden Assessment (DBA) and reports findings and recommendations, as part of the overarching Data Coordination Board (DCB) process. The DSAS oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

Detailed burden assessment findings

Assessed costs

The associated burden of the data collection is:

Burden on providers	£201,000	
Set up costs for the data collection	£0	Includes NHS Digital and supplier costs, representing a maximum estimate.
Other costs of the data collection	£84,000	

Help us to identify inappropriate collections

NHS Digital's Challenging Burden Service (CBS) offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

For more details and information on how to refer a collection, please visit:<https://digital.nhs.uk/services/the-challenging-burden-service/collection-referral-service>

Help us to improve this product

We are continually looking at ways to improve the products that we provide to our customers. By taking a few minutes to complete the following questions you will help us to improve future DPNs.

To complete the short survey, please visit:

<https://nhs-digital.citizenspace.com/rocr/ef5cf941>

For further information

www.digital.nhs.uk

0300 303 5678

enquiries@nhs.net

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