

Data Provision Notice

Mandating mortality data updates onto the Personal Demographics Service (within 1 working day of death)

Information Asset Owner: Stephen Smith

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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)(a), to require data from health or social care bodies, or organisations that provide publicly funded health or adult social care in England, where it has been directed to establish an information system by the Secretary of State for Health and Social Care or NHS England.

The data, as specified by NHS Digital in this published Data Provision Notice (DPN), is required to support a direction from the Secretary of State for Health and Social Care 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.

The requirement for mandatory updates

The purpose of this DPN is not to collect new information, it is to mandate the updating of death notifications onto the Personal Demographics Service (PDS) within 1 working day and to provide mandatory protocols for where, when, and by which organisation or clinical setting it should be reported. Therefore ensuring that the frequency, collation and submission of this information is consistent across the NHS.

As part of the ongoing response to COVID-19 and a wider action to improve data quality, the Secretary of State for Health and Social Care directed NHS Digital to investigate and implement ways in which to improve the quality, accuracy and timeliness of death notifications.

Historically there has been a circa 20% discrepancy between death notifications reported by clinical settings and those reported by both the Office for National Statistics (ONS) and the General Register Office (GRO).

While investigating the ways in which this information was traditionally recorded and submitted, it was identified that:

- In the majority of cases, death notifications are already being processed and updated onto local Patient Administration Systems (PAS) and GP clinical systems, however in some cases these systems (although capable of being so) are not linked to PDS.
- There are no historically mandated requirements for clinical settings to provide this information.
- There are no historically mandated time frames for the reporting of this information.
- There are no historic protocols stipulating who should submit this information (primacy of reporting), which has resulted in incidents where notifications have not been provided due to confusion and incorrect assumptions being made.

Benefits of mandatory updates

Operational (healthcare setting)

- clarity for health and care organisations in what is required – removal of assumption (and its associated failings) in reporting procedure
- reduce reputational risk from contacting deceased patients

- reduce risk of fraud for prescriptions
- cancellation of future appointments and other associated administrative workload
- more up to date data that can be used for GP payment calculations.

Strategic (governmental)

- consistent, timely and comparable data for decision making
- prevention of reputational damage, through the provision of accurate, time sensitive information to citizens
- support to wider death certification process
- timely notification of deaths (within 1 working day) to Medical Examiners Office.

Legal basis for the mandatory update and analysis

Collection and Analysis

NHS Digital has been directed by the Secretary of State for Health and Social Care 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 this service. A copy of the Direction is published here <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state-directions/spine-services-no-2-2014-direction>

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

In line with section 259(5) of the Act, all organisations in scope, 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 duty under section 259(8).

Transparency

NHS Digital has a Transparency Notice in place found here:
[Transparency notice: how we use your personal data - NHS Digital](#)

Persons consulted

NHS Digital has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- NHS Trusts
- British Medical Association
- Royal College of General Practitioners
- Medical Examiners
- Doctors Surgeries
- Ambulance Services
- Suppliers (PAS Systems)
- Office for National Statistics

- General Register Office.

Scope of the mandatory update

Under section 259(1)(a) 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:

- All health and social care organisations

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:

- GP Practices
- NHS Acute Trusts

Who is responsible for providing the notification?

This DPN requires PDS to be updated within one working day following the verification of the death of a patient under the care of the NHS or being informed of a death from an appropriate third party (eg notification of a death occurring outside England).

1. Hospitals
 - a. Deaths in hospital (including any allied organisation, such as a palliative care unit)
2. Surgeries
 - a. Deaths in the community, including where a death may be referred to HM Coroner or on receiving notification of a death that occurred outside England
3. Exceptions
 - a. If the death takes place outside the scope of the above list, notification will be the responsibility of the medical professional in charge of the situation.

Updates to PDS can be undertaken by any individual with the required authorisation and permissions at the organisation responsible for making the notification. This may be different to the clinician who verified the death.

The reporting organisation is responsible for ensuring that the processes are in place to enable PDS to be updated, including the authorisation of non-clinical staff to action the update.

How will the mandatory update take place?

Existing PDS update processes facilitated by in service Electronic Patient Record (EPR) systems should be fully utilised where possible. Where this option is unavailable, a number of other options can be utilised to update PDS including:

- SCRa
- FHIR API
- HL7 API

Further details, EPR user guides and additional information on FHIR and HL7 APIs are available at the following web page: <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns/mortality-data-flows>

Period of the requirement

- First mandatory submission date – 10 January 2022 (though where possible notifications / clinical settings should conform to this DPN as soon as possible).
- Submission frequency – within 1 working day of the death occurring.
- Submission end date – Ongoing.

Data quality

The data submitted will be subject to the existing and future data quality process and procedures employed by PDS

Burden of mandated updates

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 process is carried out by the Data Standards Assurance Service (DSAS) which assures burden assessment evidence as part of the overarching Data Alliance Partnership (DAPB) approval process. The DAPB, acting under authority of the Secretary of State, oversees the assurance, approval and publication of information standards and data collections for the health and social care system in England.

The data which is the subject of this DPN does not form a data collection which is in scope of that governance:

- the data is for the update of a national system in relation to one individual patient (deceased) by an individual clinician, with the DPN setting out rules of primacy and timescales
- the data is not an aggregation, at a care provider level, of information about all deceased patients within a given time period which is submitted via a collection platform to a central repository for secondary uses.

This DPN is not a request for new information, it is the mandate of a daily reporting process (that is already taking place in the majority of settings) and the defining of clear reporting protocols, in order to ensure death notification to PDS within one working day of a death.

For further information

www.digital.nhs.uk

0300 303 5678

enquiries@nhsdigital.nhs.uk

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