

Data Provision Notice

Cancer Programme Pilots Evaluation

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Background

The Health and Social Care Act 2012 (the Act) gives [NHS England](#) 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.

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

Directions are given by the Secretary of State for Health and Social Care requiring NHS England to establish and operate a system for the collection and analysis of patient-level data from Cancer Programme Pilots in England, and provide the mandatory information specified, to support local health and care systems.

This will enable NHS England to fulfil its commitments for delivering the NHS Long Term Plan (LTP) ambitions in relation to increasing cancer survival and early diagnosis rates, reducing cancer waiting times, and providing more personalised care for patients both during and after their cancer diagnosis. NHS England will use the data obtained to evaluate the safety and effectiveness of these pilot initiatives in order to:

- develop and deliver methodologies to enable faster and more efficient pilot set up and for the improved data collection from health care providers;
- evaluate the impact from pilots on patient experience, patient outcomes, and wider system outcomes;
- measure the cost effectiveness of pilots; and
- support planning and research relating to cancer outcomes.

Benefits

Benefits to NHS England:

- Improves data collection and linkage from health care providers.
- Enabling the evaluation of impact from pilots on patient experience, patient outcomes, cost effectiveness, and wider system outcomes
- Monitor the contribution of Pilots of delivering the Cancer Ambitions of the Long Term Plan.
- Enable NHS England to work with Cancer Alliances and local authorities to embed Pilots and improve their effectiveness.
- Facilitates conversations with commissioning groups about developing sustainable funding models and evidencing the wider benefits of the NHS England Cancer Programme.

Benefit to local providers in delivering cancer services:

- Reduce the burden of data collection on local service providers allowing NHS England to collect the minimum information on Cancer Programme activity and to combine that with relevant information that is already collected via existing national datasets
- Support local providers in their decision making to determine which Pilots are effective and cost-effective in meeting the NHS Long Term Plan Cancer Ambitions for earlier and faster diagnosis and improved survival by creating increased capacity through more efficient diagnostic and treatment pathway.
- Inform how Pilots should be commissioned beyond the transformation and pilot stages and ensure local reduction in unwarranted variation in referral for, access to and in the reliability of relevant diagnostic tests and treatment.

Benefits to patients:-

- Dissemination of findings and data derived from the evaluation will contribute to the Ambition of the NHS LTP to improve earlier and faster cancer diagnosis, improve survival for those diagnosed with cancer and help to deliver a better, personalised diagnostic and treatment experience for patients.

Legal basis for collection, analysis, publication and dissemination

NHS England 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. The direction and accompanying requirements specification are published on the NHS England website: <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state-directions/cancer-programme-pilots-evaluation-directions-2024>

This information is required by NHS England 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 England 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 an NHS England duty under section 259(8).

Persons consulted

Following receipt of a request to establish a system to collect Cancer Programme Pilots Evaluation data, NHS England has, as required under section 258 of the Health and Social Care Act 2012, consulted with the following persons:

- Director of the Cancer Programme – Senior Responsible Officer
- Department of Health and Social care (DHCS) – Sponsor
- Project Delivery teams - who the data will be collected from (data submitters)
- Community Pharmacy teams - who the data will be collected from (data submitters)
- Primary Care Network teams – data submitters on behalf of participating pilot sites

- Midlands and Lancashire Commissioning Support Unit – representatives of colleagues who will be using and analysing the information from the Direction (data consumers)
- Arden and GEM Commissioning Support Unit
- Patient representatives

Scope of the collection

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 England duty under section 259(8) on the following persons:

Local service providers delivering Cancer Programme Pilots in England, including:

- Project Delivery Teams commissioned locally by Integrated Care Boards to enable to the delivery of Targeted Lung Health Check Pilot.
- Community Pharmacy sites delivery the Community Pharmacy Consultation Service Pilot.
- General Practice sites within Primary Care Networks taking part in the Pancreatic Cancer Case Finding Pilot.

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

Form of the collection

The requirement relates to the extraction, submission and linking of patient identifiable data with national datasets.

Full details of the data to be submitted for each Cancer Programme Pilot can be found in the individual Pilot Technical Output Specifications.

Manner of the collection

The Data collection processes for each Cancer Programme Pilot is detailed in the Technical Output Specifications.

Cancer Programme Pilot local providers must share data as set out in the Technical Output Specifications. Therefore, providers must:

- Collate and extract data as per the Technical Output Specification.
- Structure the data and create a data submission file as per the Technical Output Specification.
- Apply the basic validation rules and ensure that the submission file conforms to these, as per the Technical Output Specification.
- Ensure the data submission file only contains data that relates to the specified reporting period and relates to one provider organisation.
- Submit data submission files as set out in the Technical Output Specification.

Period of the collection

The data collection will cover the period of the evaluation for each of the Cancer Programme Pilots. This is set out in the Technical Output Specification.

Data quality

NHS England is committed to supporting local care providers at the point of submission investigating any unexpected variations in data in order to improve data quality. Also following submission, NHS England will work with providers where there are concerns with data quality to improve future submissions.

As per the Requirements Specification, providers of Cancer Programme pilots must review the Technical Output Specification to understand the data quality rules that will be applied to each data group on arrival at the data landing platform.

Data quality issues will be highlighted and shared back with providers for them to take further action and resubmit data if necessary.

Burden of the collection

Steps taken by NHS England to minimise the burden of collection

NHS England has a statutory duty under section 253(2) of the Act to seek to minimise the burden it imposes on others. In seeking to meet these obligations in relation to this collection, NHS England has:

- Consulted with local providers, Cancer Alliances, and CSUs to ensure that the minimum amount of data items are included in the collection.
- Explored where data already exists in National datasets, to reduce the need of re-collecting it through the Pilot datasets. This Direction will allow the Pilot datasets to be linked with these National datasets.

In addition, in support of its obligation under 265(3) of the Act, NHS England 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 Board (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.

In this case, the burden assessment carried out by the Data Standards Assurance Service (DSAS) is not required, because the Cancer Programme Pilots datasets are not National datasets.

Assessed costs

There is not additional associated burden of data collection costs. The costs are included within the budgets provided to local providers for setting up their Pilots.