



Public Health England

Protecting and improving the nation's health

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Sarah Wilkinson
Chief Executive
NHS Digital
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14 June 2019

Dear Sarah,

I am writing on behalf of the Secretary of State for Health and Social Care ('the Secretary of State') to direct the Health and Social Care Information Centre, known as and referred to in this Direction as NHS Digital, to establish and operate an informatics system for the collection and analysis of cancer registration information from Public Health England (PHE).

The purpose of this Direction is to enable NHS Digital to collect cancer registration information from PHE, link this information to other information controlled by NHS Digital for the purpose of providing population cohort health event notification services, and to disseminate this linked information to approved applicants for the population cohort health event notification services provided by NHS Digital.

'Approved applicants' are persons or organisations who have been approved under such data dissemination systems and procedures as may be established by NHS Digital.

PHE is an executive agency of the Department of Health and Social Care. It fulfils the Secretary of State's statutory duties to protect health and address health inequalities, and executes the Secretary of State's power to promote the health and wellbeing of the nation.

PHE's annual remit letter from the Parliamentary Under Secretary of State for Public Health and Primary Care sets out its responsibility for the national disease registers. This includes the national cancer register, which processes confidential patient information on the diagnosis, treatment and outcomes of patients with cancer in England. PHE has approval from the Secretary of State to process this confidential patient information without consent under Regulation 2 of the Health Service (Control of Patient Information) Regulations 2002.

This Direction is given to NHS Digital in exercise of the powers of the Secretary of State conferred by sections 254(1) and (6), and 304(9), (10) and (12)(a)(v) of the Health and Social Care Act 2012 ('the Act').

In accordance with section 254(2)(b) of the Act, the Secretary of State considers it to be in the interests of the health service in England for this Direction to be given.

This Direction is to be known as the **Cancer Registration Information (NHS Digital Cohort Health Event Notification Service Dissemination) Direction 2019** and comes into force on 14 June 2019.

Under section 254 of the Act, NHS Digital is directed to:

- Collect confidential patient information¹ from PHE on patients recorded on the national cancer register; the specification for this collection is set out in Annex 1 of this Direction and may be revised from time to time, as jointly agreed in writing by NHS Digital and PHE.
- Collect this confidential patient information from PHE on a monthly basis; this collection frequency may be revised from time to time, as jointly agreed in writing by NHS Digital and PHE.
- Link this information to other information controlled by NHS Digital for a range of purposes including, but not limited to, providing cohort health event notifications, managing research study cohorts, and identifying eligible participants for clinical trials.
- Provide ad hoc query resolution to ensure the accurate linkage of PHE cancer registration information to the correct patients in the NHS Digital population cohort health event notification service, and to ensure the accuracy and consistency of population cohort health event notification service data.

NHS Digital is directed in accordance with section 260(2)(d) of the Act not to publish the information obtained by complying with this Direction.

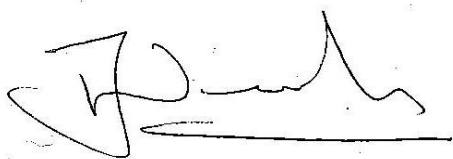
In accordance with section 261(3) of the Act, NHS Digital may disseminate the information obtained by complying with this Direction, where this information has been linked to other information controlled by NHS Digital for the purposes outlined in the list above of providing population cohort health event notification services, in line with its statutory powers to approved applicants of these services.

Under section 262(5), NHS Digital is directed not to exercise its power under section 261(1) or (4) of the Act to disseminate the information obtained by complying with this Direction if this information is not linked to other information controlled by NHS Digital. NHS Digital agrees not to exercise any other powers it has under the Act or any other Act to disseminate the information obtained by complying with this Direction if this information is not linked to other information controlled by NHS Digital.

In accordance with section 254(5) of the Act, NHS Digital has been consulted before this Direction has been given.

¹ Confidential patient information in this Direction has the same meaning as in section 251(11) of the National Health Service Act 2006.

Yours sincerely,



Professor John Newton
Director of Health Improvement

Annex 1: Information to be collected by NHS Digital under this Direction from PHE for patients recorded on the national cancer register

Data item name	Data item description
NHS NUMBER	The NHS Number of the patient
PATIENT NAME	The family name of the patient
PATIENT FORENAME	The first given name of the patient
PATIENT OTHER INITIALS	The initials of any other forenames of the patient
MAIDEN NAME	The previous family name of the patient, if applicable
SEX	The sex of the patient
DATE OF BIRTH	The date of birth of the patient in the DDMMYYYY format
DATE OF DEATH	The date of death of the patient, if applicable
PATIENT ADDRESS	The usual address and postcode of the patient
CANCER NUMBER	An 11-digit unique system-generated identifier for the patient consisting of 4 characters identifying the PHE cancer register office where the case was recorded, the year in which it was recorded (1971 onwards) and a 5-digit consecutive serial number
ANNIVERSARY YEAR	The year in which the patient was diagnosed
ANNIVERSARY MONTH	The month in which the patient was diagnosed
ANNIVERSARY DAY	The day on which the patient was diagnosed
CANCER SITE	A code representing the anatomical site of the cancer using the International Classification of Diseases (ICD) coding system
TYPE OF GROWTH	A code representing the type of tumour using the ICD Oncology (ICD-O) coding system
BEHAVIOUR OF GROWTH	A code representing the status of the tumour (malignant, in situ, benign, etc.) using the ICD-O coding system
MULTIPLE CANCER INDICATOR	A flag to indicate if the patient previous has tumours recorded in the national cancer register