NHS Health Check Data Extraction and General Practice: Frequently Asked Questions

4 May 2018

Audience

This information is for general practices that provide NHS Health Checks.

Background

Starting in June 2018, NHS Digital, acting on behalf of Public Health England (PHE), will be collecting information about people who are invited to an NHS Health Check. The information will contain the results of people who did or did not attend. This information will be extracted in mid-2018 using the General Practice Extraction Service (GPES) run by NHS Digital.

How will this information be shared?

The data collected will be analysed by PHE and reports of the main findings will be available on <u>the NHS Health Check webpage</u>. The data will also be analysed to inform PHE's partners and other professionals involved in the programme, including the Department of Health, commissioners and professional groups who provide NHS Health Checks.

What type of data will be extracted?

We will be using patient records held by GPs. The records will be collected via GPES and will concern information about people who have been invited for and attended an NHS Health Check, <u>and</u> people who have been invited for but <u>not</u> attended an NHS Health Check since 2009.

Before the information is received by PHE, all patient information will be pseudonymised in line with the Information Commissioner's Office (ICO) Anonymisation Code of Practice. This means that the identifying fields within the data such as date of birth, NHS number and postcode details will be replaced with an artificial identifier. In this case a unique number. Therefore, PHE will not receive personal data.

PHE will be using information from records for patients aged 40-74 years (the age group that the NHS Health Check is aimed at), and people aged 18-39 years who have been invited for and/or attended an NHS Health Check. This will provide information about cases where people may have been invited and/or attended an NHS Health Check before reaching the eligible age of 40.

PHE is collecting data for four patient cohorts:

Cohort 1: registered patients aged 40-74 invited to an NHS Health Check only. Cohort 2: registered patients aged 40-74 years who either commenced, completed (by a GP or third party), declined or did not attend an NHS Health Check. Cohort 3: registered patients aged 40-74 years for whom an NHS Health Check was inappropriate.

Cohort 4: registered patients aged 18-39 years who have either been invited for an NHS Health Check and/or completed an NHS Health Check.

Each patient will be included in one of these four cohorts according to the information in their medical record.

A unique number will be created for each patient. This means that each patient will have a pseudonymised ID which PHE can use to analyse information instead of their personal details. Therefore, any data used by PHE will be pseudonymised.

NHS Digital will collect the following information for each patient:

- NHS number (this information will not be passed on to PHE)
- date of birth (this information will not be passed on to PHE), though age at time of the extract will)
- postcode (this information will not be passed on to PHE)
- gender
- patient active status
- general practice code
- date patient registered with the general practice
- date of death (if applicable) (this information will not be passed on to PHE)
- ethnicity
- first language (and whether an interpreter was needed)
- country of birth
- carer status
- diagnoses for disabilities: such as learning disability, serious mental illness, blindness, severe deafness

NHS Digital will extract information from GPES that relates to the risk factors and health conditions that the NHS Health Check programme seeks to manage, prevent or diagnose:

- smoking status
- family history of coronary heart disease
- body mass index (BMI) score
- cholesterol level
- blood pressure
- physical activity levels
- risk of cardiovascular disease
- alcohol use
- tests for cardiovascular disease risk factors
- cardiovascular disease diagnoses
- information on the advice or other information provided to the patient such as advice around diet
- information on any medication prescribed for cardiovascular disease

• information on referrals made to a range of lifestyle intervention/ programmes following a NHS Health Check

Who is collecting the data and how is it collected?

The General Practice Extraction Service (GPES) at NHS Digital will extract the data from general practice (GP) patient records. NHS Digital will pseudonymise the information prior to providing it to PHE.

Why is this information being collected?

PHE wants to use the information collected in order to monitor access to the NHS Health Check programme for people living in a geographical area, as well as the number of people in different communities who are attending an NHS Health Check when they are invited. It will also help to measure how well the programme is being run across England and whether it is having an impact on the health of local people.

To date, this information has not been collected on a national scale.

The data will also be analysed to inform our partners and other professionals involved in the programme, including the Department of Health and Social Care, commissioners and professional groups who provide NHS Health Checks.

If any statistics or reports using this data are published, PHE will observe <u>Government</u> <u>standards</u> that ensure that individuals cannot be identified from published data. In addition, GP practices will not be identifiable in reports published by PHE.

What does this extract mean for the local authority quarterly returns of data on offers and uptake?

Local authorities will still need to submit quarterly data returns on offers and uptake for the NHS Health Check, as this is still a statutory requirement, and will remain the only method to obtain timely information on programme quarterly activity.

How will the data be used?

- to provide information on how the NHS Health Check programme is performing
- to show how the programme is performing in different areas of England
- to highlight opportunities for improvement in how the NHS Health Check programme is delivered
- in the future, PHE plans to use this data to track how the NHS Health Check programme has made a difference to the long-term health of patients

The data collected will not be used by PHE to measure/monitor local authorities against the prescribed functions as per the terms of the public health grant.

What happens to the data prior to being sent to PHE?

All confidential personal information such as NHS number, date of birth and postcode will be removed, and a unique ID will be created. PHE will not receive any personal information.

In order to allow PHE to track how the NHS Health Check programme has impacted the long-term health of patients, at a later stage PHE might seek to link the information we are collecting with other information such as hospital records. To allow linkage at a later stage NHS Digital will keep a copy of the patient identifiers. It is anticipated that the linkage, subject to approval, would be done by NHS Digital, using the unique ID to link records.

Who will the data be shared with?

No individual patient information will be shared or made publicly available. PHE will share its findings with local authorities and these will also be publically available. These findings will be aggregated in accordance with PHE standard for Statistical Disclosure Control to ensure that individuals cannot be identified from any published data. Individual GP practices will not be identifiable.

How will this affect the patients concerned?

There will be no impact on patients from sharing the data, as no one can be identified from the information shown in our reports.

What if patients do not want their data to be collected?

If patients do not wish their data to be collected, they can contact their GP to register a Type 1 opt-out. This is an objection that prevents an individual's personal confidential information from being shared outside of their general practice except when it is being used for the purposes of direct care, or in particular circumstances required by law, such as a public health emergency like an outbreak of a pandemic disease.

NHS Digital will uphold Type 1 opt-outs in collecting these data from general practices (that is: any patients who have registered a Type 1 opt-out prior to the point in time at which this data collection takes place will not be included in this data collection).

A Type 2 opt-out is an objection that prevents an individual's personal confidential information from being shared outside of NHS Digital, except when it is being used for the purposes of direct care. Type 2 opt-outs do not apply to this data collection as no personal data will leave NHS Digital.

Read more about personal information choices online.

Who agreed to the extract taking place?

This data collection has been subject to extensive consultation as part of the Standardisation Committee for Care Information (SCCI) governance process. An initial SCCI targeted consultation took place between 24 October 2016 and 7 November 2016.

The Joint General Practitioners Committee (GPC) and Royal College of General Practitioners IT subcommittee (also referred to as the Joint GP IT Committee) were chosen as the appropriate group to consult with on this data collection as they have representation from both the British Medical Association (BMA) and the RCGP. The Joint GP IT Committee is part of the BMA GPC, which is the only body that represents all GPs in the UK. From 1 April 2017 the Data Coordination Board (DCB) took over responsibility for the approval of standards from the SCCI, DCB is a sub-group of the Digital Delivery Board.

What is the legal basis for the data extract happening?

The legal basis for the data extract is the Secretary of State Direction. The Direction instructs NHS Digital with the *legal requirement* to carry out the extract.

How will GPs know that the extract is taking place?

GPs will be informed that the extract is taking place via the Data Provision Notice (DPN) and the Privacy Notice. These will be issued at the same time to general practices, at least six weeks before the extraction takes place.

What is the Data Provision Notice (DPN?)

The DPN is used by NHS Digital when it is using its statutory power to collect data-in the case of this extract, as stipulated in the Direction. The DPN provides information to providers about the data extraction, including its purpose and benefits, as well as information governance and legal considerations.

What is the Privacy Notice?

The Privacy Notice serves two purposes:

- It ensures that NHS Digital meets its legal duty in line with the Data Protection Act 1998/Data Protection regulations. NHS Digital, as Data Controller of the personal data that are collected, must issue a Privacy Notice to clearly set out how, and why it is using patients' personal data, as well as what personal data are being used.
- 2. It supports general practices in meeting their legal duty in line with the Data Protection Act 1998/Data Protection regulations.

As Data Controller of their patients' personal data, general practices have a legal duty to provide patients with fair processing information. To meet their legal fair processing duty for this data collection, general practices are required to:

- inform their patients how their personal data will be used
- reassure their patients that their personal data will remain safe and confidential and will be used only for its intended purpose
- allow patients to opt-out of sharing their personal data should they choose to do so.

The information included in the Privacy Notice allows general practices to meet their fair processing duties.

What if my local authority is collecting and analysing data in some other way?

Local authorities should still collect and analyse data locally if they need access to timely information on their local programme activity.

What will the burden of the data extract be on general practice?

This will be minimal. Essentially, general practices will be asked for their consent to the data leaving their practices, using GPES. There is no new data recording burden on general practice as a result of this extract.

Does general practice usually participate in data extracts?

Yes. Usually 98-99% of practices participate in data extracts when a Secretary of State Direction forms the legal basis for the extract.

Are GPs involved in this data extract process?

Yes. The Royal College of General Practitioners (RCGP) and the British Medical Association (BMA) both provided consultation responses to earlier drafts of the data extract specifications, and this shaped the final version of the extract. Both the RCGP and the BMA are members of the Data Extraction Advisory Committee (DEAC) for this data extraction. The role of DEAC is to guide how the data extract will be used for the purpose of monitoring the reach, implementation and impact of the NHS Health Check programme.

Will this data extract happen again?

At this point, the DCB has given consent for the data extract to take place until 30 June 2018. After this date, further data extract requests would be subject to further review and assurance processes before another extract could take place.

Will the extract be only collecting data from general practice?

Yes. However, the data extract will include codes that indicate a third party (non-GP) provider of the NHS Health Check. These will be instances in which the NHS Health Check has been recorded in the general practice record as being invited for/commenced/ completed/did not attend NHS Health Check with a third party provider.

Can general practice see the Read codes/data item descriptions being extracted?

Yes. The Read codes/data item descriptions are available on the NHS Digital website, alongside the other published information on the data extract.

Do these codes form a new national data set or data standard for the NHS Health Check?

No. At this stage, no new national data set or data standard has been agreed for the NHS Health Check. The list of codes used for the extract was built to ensure all possible information on specific data item was captured. We will extract data dating back several years: some of the codes listed might have been appropriate in the past but not be the best codes to use anymore.

Is there any information for patients?

Yes. PHE has developed a patient information notice for patients. This is also posted on the NHS Health Check website. GPs can use that patient information notice or create their own. There is also an easy read version of the patient information notice, also available on the NHS Health Check website.

Further information

For further information, please see:

- Patient information notice: NHS Health Check Data Extraction
- Patient information notice: NHS Health Check Data Extraction (Easy read version)

Also see the <u>NHS Digital landing page</u> for the extract. This page provides information on the Privacy Notice: NHS Health Check for adults aged 40-74 years.

How will you recognise from GP records that a patient had completed or been offered a check?

Early investigation by NHS Digital suggests that the recording of coding for NHS Health Check invitations and attendances are high in general practice. However, PHE appreciates that the relevant clinical codes would not have been widely used at the start of the programme, so it is likely that, for the earlier years, there will be limitations in the completeness of the data.

Clinical coding can be very complex to interpret, how will PHE interpret its findings?

We have set up a Data Extract Advisory Committee (DEAC) to help guide how the data extract will be used for the purpose of monitoring the reach, implementation and impact of the NHS Health Check programme. The committee is tasked with providing advice and guidance to help take the data through the stages of analysis and into tangible uses for its critical audiences and stakeholders. DEAC is a subgroup of the NHS Health Check Expert Scientific Clinical Advisory Panel.

Membership can be found <u>here</u>.

Will local authorities be able to request from PHE access to the data for their own area?

PHE will not share patient level data but will publish findings aggregated at local authority level. In publishing any statistics and reports from the extract, PHE will observe the PHE standard for Statistical Disclosure Control to ensure that individuals cannot be identified from any published data.

When will data be published from the extract?

PHE will aim to publish aggregated findings from the extract in the 2019 calendar year.