



## **Guidance Note**

# NHS Digital "Data Scrape" (opt out)

### Introduction

This guidance is to support practices when responding to concerns from patients regarding data sharing and to inform responses to patients asking to "opt out" of any sharing agreements.

### Background

Earlier this year the Dept of Health in England announced plans to undertake a mass data extraction from GP records as part of their "General Practice Data for Planning and Research" (GPDPR) programme. As of 1<sup>st</sup> July 21, pseudonymised data would be collected by NHS Digital, although they would retain the ability to reidentify the data if they had a valid legal reason to do so. Patients were initially given until 23<sup>rd</sup> June 21 to submit a Type 1 opt out form to their GP to avoid their data being shared. Due to concerns raised by privacy groups that patients were not given enough time to make an informed decision the Westminster Government has postponed the extraction until 1<sup>st</sup> Sept 21 to allow patients more time to consider this.

### Will this affect any of my patients?

This will not affect patients in NHS Scotland as health is devolved and NHS Digital have no jurisdiction in Scotland therefore no NHS Scotland patient data will be shared with NHS Digital. Any patient registered with a GP in Scotland will not require to opt out as their data is held separately within NHS Scotland systems.

NHS Lothian Information Governance Guidance Note – opt out Version 1.0 (Final) June 21

### What should I do if the patient submits a Type 1 opt out form?

It's important to read the form carefully to see what the patient has written. If they have asked to opt out of the NHS Digital extraction, then you can inform them that their data is already safe as mentioned above. If they are less specific and request to opt out of "all sharing", you'll need to identify which sharing your practice has agreed to and whether it can be opted out of. Some sharing is required for healthcare purposes so can't be opted out of, whereas some sharing is based on consent.

#### Who can they ask about data sharing in Scotland?

National Services Scotland are the organisation who are responsible for projects that affect all health boards in Scotland, like data sharing for national systems. If patients are concerned about any sharing taking place nationally, they can contact:

NSS Data Protection Officer Gyle Square 1 South Gyle Crescent Edinburgh EH12 9EB Tel: 0131 275 6000 Email: <u>nss.dataprotection@nhs.scot</u>

## Public Health Scotland (PHS)

In 2017, Public Health Scotland's predecessor organisation had extensive engagement with the public as well as privacy groups to agree on a controlled way to extract specific data items from GP Practice systems for specific purposes. The extract that PHS receives excludes all confidential discussions between the patient and GP. This data enables it to carry out the activities which are outlined in its <u>functions</u>. This legislation empowers PHS to undertake, amongst other things, research and development services in the field of public health. It also empowers PHS to engage in, and support, research into any matter relating to the causation, prevention, diagnosis, or treatment of illness. You can read more about the range of research studies that PHS has led, collaborated on or supported <u>here</u>. GP Practices have the option to opt out of sharing with PHS, and the patients of practices who do share also have the option to have their data removed from the extract sent to PHS.

NHS Lothian Information Governance Guidance Note – opt out Version 1.0 (Final) June 21

#### **Be Proactive**

Patients may be anxious about this, and it has generated a lot of media attention. To reassure your patients we'd recommend adding a notice to the front page of your practice website – we've provided sample wording that you can use in its entirety if you wish:

#### **\*PATIENT NOTICE**\*

#### NHS DIGITAL DATA SHARING OPT OUT

We would like to reassure our patients that the proposed extraction of GP data by NHS Digital does **NOT** include any patients registered with this practice or in NHS Scotland. NHS Digital provide services in England so are not able to access any data held in Scotland. You are not required to opt out as your data is already safe. We take patient confidentiality extremely seriously and safeguards are in place to protect this, including when data is used for research.

Further information on how NHS Scotland handles your personal information is on the NHS Inform website: <u>How the NHS handles your personal health information | NHS inform</u>.

If you would like to discuss this further, please contact:

[Practice manager]