

# **Important information on Patient Data**

Version 1 - March 2020



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The Secretary of State for Health and Social Care is writing to GP practices in England, whose IT systems are supplied by The Phoenix Partnership (TPP) or Egton Medical Information Systems (EMIS), requiring them to release primary care patient data, in respect of UK Biobank's consented participants only, to UK Biobank.

This is for purposes set out in the Health Service (Control of Patient Information) Regulations 2002 (COPI).

The notice (Appendix 1) requires all GP practices, whose IT systems are supplied by TPP or EMIS, to release the relevant primary care data to UK Biobank for purposes related to the outbreak of COVID-19.

Please see additional information (Appendix 2) to implement the COPI Notice.



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**Appendix 1: Notice** 



39 Victoria Street London SW1H 0EU

23rd March 2020

To all GP Practices in England whose IT systems are supplied by TPP or EMIS

Notice under Regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (COPI), which were made under sections 60 (now section 251 of the NHS Act 2006) and 64 of the Health and Social Care Act 2001.

The health and social care system is taking extensive action to manage and mitigate the spread and impact of the current outbreak of COVID-19. Today, I am writing to GP practices in England, whose IT systems are supplied by The Phoenix Partnership (TPP) or Egton Medical Information Systems (EMIS), under Regulation 3(4) of COPI to require them to release primary care patient data, in respect of UK Biobank's consented participants only, to UK Biobank, for the purposes set out in Regulation 3(1) of COPI.

This notice requires all GP practices, whose IT systems are supplied by TPP or EMIS, to instruct them to release the relevant primary care data to UK Biobank for purposes related to the outbreak of COVID-19.

This Notice will be reviewed on or before 30 September 2020 and may be extended by me by further notice in writing for the period specified in that notice. If no further notice is sent to you by me, this Notice will expire on 30 September 2020.

Purposes related to the outbreak of COVID-19 include, but are not limited to, the following:

- understanding Covid-19 and risks to public health, trends in Covid-19 and such risks, and controlling and preventing the spread of Covid-19 and such risks;
- identifying and understanding information about patients or potential patients with or at
  risk of Covid-19, information about incidents of patient exposure to Covid-19 and the
  management of patients with or at risk of Covid-19 including: locating, contacting,
  screening, flagging and monitoring such patients and collecting information about and
  providing services in relation to testing, diagnosis, self-isolation, fitness to work,
  treatment, medical and social interventions and recovery from Covid-19;
- understanding information about patient access to health services and adult social care services and the need for wider care of patients and vulnerable groups as a direct or indirect result of Covid-19 and the availability and capacity of those services or that care;
- monitoring and managing the response to Covid-19 by health and social care bodies and the Government including providing information to the public about Covid-19 and its effectiveness and information about capacity, medicines, equipment, supplies, services and the workforce within the health services and adult social care services;
- delivering services and information to patients, clinicians, the health services and adult social care services workforce and the public about and in connection with Covid-19, including the provision of information, fit notes and the provision of health care and adult social care services; and
- research and planning in relation to Covid-19.



A record should be kept of all data processed under this notice.

#### Why are we doing this

UK Biobank has explicit consent from all its c.500,000 participants to be provided with, hold and process their health care records (both primary and secondary).

UK Biobank has secured frequent feeds from Public Health England for the confirmed COVID-19 cases and these data will be incorporated into the main UK Biobank database for researchers to study determinants of COVID-19 infection. However, as the COVID-19 situation worsens it is likely that many presumed cases will not be tested (especially among the elderly) and many individuals will remain at home (even when their symptoms are severe).

Consequently, the ability of UK Biobank to be able also to incorporate primary care data into its resource is likely to be of enormous value to obtain a more complete assessment of the determinants of COVID-19 outcomes. This is something that we need to do now.

### Key points

- The validity of UK Biobank's participant consent for this purpose has been reviewed and endorsed by the Information Commissioner's Office;
- · Only primary care data from UK Biobank's consented participants will be extracted;
- The proposed extraction is fully consistent with the provisions of the GDPR;
- UK Biobank only release de-identified data to its approved researchers (for the conduct of health-related research, relating to COVID-19 in this case, which is in the public interest) and so patient confidentiality is maintained;
- The extraction will relate to the primary care coded data, including data on diagnoses (important for co-morbidities), on prescriptions (important for drug interactions) and on investigations (for pathology reports);
- Following the instruction provided above, there is no further action that any GP practice needs to undertake; and
- This Notice is limited to those GP practices whose IT systems are supplied by TPP or EMIS because UK Biobank has appropriate agreements in place with these companies.

Yours sincerely,

s. P. Madde

On behalf of

Secretary of State for Health and Social Care



### Appendix 2: Additional information to implement the COPI Notice

Publications approval reference: 001559



## Additional information to implement the COPI Notice

The health and social care system is going to face significant pressures in the coming months due to the COVID-19 outbreak.

The Secretary of State for Health and Social Care has Directed NHS Digital to collect and analyse data from providers and other organisations involved in managing the Covid-19 response and then disseminate information and analysis to other bodies for the purpose of planning and managing the response. NHS England and NHS Improvement have already been given legal notice to support the processing and sharing of information to help the Covid-19 response under Health Service Control of Patient Information Regulations 2002. Other healthcare organisations, Arms Length Bodies (except NHS Digital and NHS England and NHS Improvement which have been separately notified) and Local Authorities have also already been given legal notice under the same regulations to support the processing and sharing of information to help the COVID-19 response. This is to ensure that confidential patient information can be used and shared appropriately and lawfully for purposes related to the Covid-19 response

In addition, to further support this the Secretary of State for Health and Social Care has issued a further notice to GP practices whose IT systems are supplied by TPP or EMIS to require them to enable UK Biobank access to data on patients who have consented to be part of the Biobank Programme. The data will be used for the purpose of responding to COVID-19. The notice **only applies** to GP practices with IT systems provided by TPP or EMIS as UK Biobank has established extraction processes with these companies.

This notice will be reviewed on or before 30 September 2020 and may be extended by further notice in writing. If no further notice is sent it will expire on 30 September 2020.

Data controllers are still required to comply with relevant and appropriate data protection standards and to ensure within reason that they operate within statutory and regulatory boundaries. The General Data Protection Regulations (GDPR) allow health data to be used as long as one or more of the conditions under Art. 6 and Art. 9 are met. There are conditions under both Articles which can be relied on for the sharing of health and care data – including consent and 'the care and treatment of patients' and 'public health'. We would expect any organisation to disseminate information within legal requirements set out under GDPR

NHSX is building up information governance resources and information on this section of the NHSX website Please check back regularly and help us to spread the word.