Privacy Notice

Research Study Title: Community-based VIrtual Electronic Wards for remote monitoring in suspected cases of COVID-19 (coronavirus): C-VIEW Study

Reference Number: DARS-NIC-396113-N9L4L

Imperial College London is the sponsor for this study based in the United Kingdom. We will be using pseudonymised data provided by NHS Digital in order to undertake this study and will act as the joint data controller together with NHS England for this study. Being a Joint data controller means that Imperial College London and NHS England are jointly responsible for looking after the data and using it properly.

For the purpose of this study, Imperial College London is supporting a programme of urgent COVID-19 work regarding new pathways of care for COVID-19 patients. The work will explore the value of a new care pathway using virtual wards with remote monitoring in suspected cases of COVID-19 in the community to improve 1) health resource utilisation (e.g. hospital admissions, ITU admissions), 2) clinical outcomes and 3) cost-effectiveness through early detection of clinical deterioration. The work is led by NHS England with NHS Digital assisting on data set provision (https://digital.nhs.uk/services/data-access-request-service-dars). Data associated with this study will be held and processed within the Imperial College Big Data and Analytical Unit Secure Environment (BDAU SE), with computer and data assets residing solely in the United Kingdom.

In response to the Covid-19 pandemic the Secretary of State for Health and Social Care issued NHS Digital with a Control of Patient Information Notice (COPI Notice) with regard to the release and processing of patient data relating to Covid-19. Data will be held within the BDAU SE for only as long as necessary to complete the processing of data for this study. This will be in line with the data sharing agreement expiry date approved by NHS Digital and the COPI Notice (current expiry date: 30/03/2021). Data will be destroyed at the request of NHS Digital according to the terms and conditions of the data sharing agreement. Further information on Imperial College London's retention periods may be found at https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf. Long-term retention will apply only to data anonymised according to ICO guidance which falls outside the remit of General Data Protection Regulation (GDPR).

The BDAU SE is an ISO 27001:2013 certified research environment which provides appropriate safeguards both in terms of technological security but also in terms in process and procedure relating to the use of your information. Access to data is allowed only to persons with appropriate legal obligations to maintain the protection of that data and those persons are trained on how to appropriately handle data. Furthermore, data is reduced to the minimum required dataset for the purposes of processing as per GDPR guidance. Datasets created as a result of processing are fully anonymised according to ICO guidance which then permits their onward use for secondary purposes such as publications and other academic outputs.

Data processing in the BDAU SE complies with all guidance provided by Imperial College London. A link to Imperial College London's data protection webpage may be found at https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/ but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

PROCESSING OF DATA

Data will be accessed and processed by Imperial College London within the BDAU SE. This includes de-identified patient level analysis of personal health information related to patients managed on a pilot virtual ward or remote community monitoring observational trial for proven or suspected high-risk of COVID-19, therefore a special category of information under GDPR Imperial College London will be the sole data processor for this study.

The primary outcome measure is to evaluate any hospital admissions or attendances by days 14 and 28. These time points have been chosen as it is reported that most COVID-19 cases have recovered by day 14. The additional time point allows evaluation of more severe cases. Secondary outcome measures include: (i) intensive care transfer, (ii) hospital length of stay, (iii) mortality/survival, (iv) oxygen therapy (v) requirement for invasive/non-invasive ventilation and (vi) cost-effectiveness. Clinical variables for measurement as secondary outcomes are: - Time from first symptom to hospital admission - Predictors: Comorbidities, age, sex, BMI, ethnicity - Thresholds/trigger values for face to face or hospital review - Disability at 3 months after hospital discharge.

The detailed purposes of processing for this study (reference number: DARS-NIC-396113-N9L4L) can also be obtained on request by contacting us as per the details in the Contact Us section or from the NHS Digital Register of Approved Data Releases (https://digital.nhs.uk/services/data-access-request-service-dars/register-of-approved-datareleases).

YOUR RIGHTS

Due to data being de-identified, we are not able to uphold certain obligations which would apply to identifiable data. This includes any process which would require re-identification of participants such as data subject access requests and the right to opt-out of data sharing. In cases where such requests are made we will make all reasonable attempts to redirect you to the responsible authority for the data. We will also make all reasonable attempts to protect your data from re-identification and any suspected or actual re-identification will be reported as a breach as required by GDPR

LEGAL BASIS

As a university, we process pseudonymised information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use pseudonymised data which is considered personal data. The data provided to us and covered by this privacy notice will be processed under General Data Protection Regulation Article 9 (2) (h) (https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/) and General Data Protection Regulation Article 6 (1) (e) (https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/), and will be disseminated under Health and Social Care Act 2012 - s261(5)(d) (https://www.legislation.gov.uk/ukpga/2012/7/section/261) and CV19: Regulation 3 (4) of the Health Service (Control of Patient Information) Regulations 2002 (https://www.gov.uk/government/publications/coronavirus-covid-19-notification-of-data-controllers-to-share-information/coronavirus-covid-19-notice-under-regulation-34-of-the-health-service-control-of-patient-information-regulations-2002-general).

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

CONTACT US

The research team conducting this study can be reached by emailing bdau@imperial.ac.uk for any further clarifications.

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (Imperial College London) first before involving the regulator.