

資料治理概念下的防疫個資應用與界線



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臺大醫院國際會議中心

前言

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□ 演說重點

- 科技防疫作為科技治理的一環
- 科學研究作為科技防疫的一環
- 資料治理作為資料應用的核心
- 公部門資料釋出再利用：科學研究
- 資料分享
- 資料利他



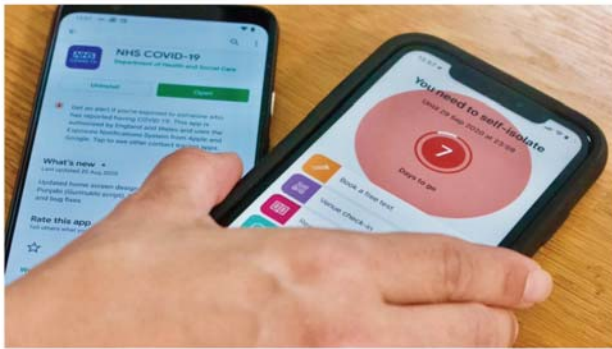
科技防疫作為科技治理的一環

Covid contact-tracing app not sharing data with police

By Zoe Kleinman
Technology reporter

© 19 October 2020

Coronavirus pandemic



The developers of the Covid-19 contact-tracing app for England and Wales have stressed that none of the data it uses will be shared with the police.

NHS COVID-19 app
@NHSCOV19app

#NHSCOV19app users are anonymous and the app cannot force them to self-isolate or identify them if they are not self-isolating.

The app cannot be used to track your location, for law enforcement, or to monitor self-isolation and social distancing. 1/2



7:36 PM · Oct 18, 2020

124 See the latest COVID-19 information on Twitter

Tweet your reply

- 不是DPA 2018/GDPR，而是 Investigatory Powers Act 2016/LED！



科學研究作為科技防疫的一環

疾管署捐血人血清抗體 研究調查計畫說明

“

- 為防堵Delta變異株入侵社區，已於今年8月23日啟動COVID-19加強監測方案，將針對今年4月25日至7月3日全臺各捐血中心之血清存檔樣本，隨機抽樣共5,000件。
- 於該段時間捐血人欲退出本計畫，請於10月18日前致電1922並請留下相關資料(血袋號碼，或提供姓名、身分證字號及生日)。

”



科學研究作為科技防疫的一環

4. 國際上也有用捐血人血清抗體陽性進行調查嗎？

A：去年(2020年5月)，世界衛生組織(WHO)已公告血清流行病學監測指引，供各國參考。英國公共衛生部定期抗體監測計畫，亦利用去連結之捐血者血液存檔樣本進行。截止至今，許多國家(包括美國、中國、澳洲、義大利)都已進行捐血者血清抗體之調查，作為防疫政策參考依據。



科學研究作為科技防疫的一環

Antibody tests are to be widely offered to the UK public for the first time in a new programme that aims to find out more about how much natural protection people have after getting coronavirus.

The government scheme will offer tests to thousands of adults each day.

Anyone over 18 will be able to opt in when having a PCR test from Tuesday - of those who test positive, up to 8,000 will be sent two home antibody tests.

Health Secretary Sajid Javid said it would be quick and easy to take part.

The first of the finger-prick tests would have to be done as soon as possible after the positive result, so the body would not have time to generate a detectable antibody response to the infection.

The second would be taken 28 days later and measure antibodies generated in response to the infection.



Covid: Antibody tests offered to public for first time

© 22 August

Coronavirus pandemic



科學研究作為科技防疫的一環

Office for National Statistics

Release calendar | Methodology | Media | About | Blog

English (EN) | Cymraeg (CY)

Home | Business, industry and trade | Economy | Employment and labour market | People, population and community | Taking part in a survey?

Search for a keyword(s) or time series ID

Home > People, population and community > Health and social care > Coronavirus (COVID-19) > COVID-19 Infection Survey: methods and further information

COVID-19 Infection Survey: methods and further information

This methodology guide is intended to provide information on the methods used to collect the data, process it, and calculate the statistics produced from the COVID-19 Infection Survey.

Contact: Kara Steel and Philippa Haughton | Last revised: 24 August 2021

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Print this methodology

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科學研究作為科技防疫的一環

Coronavirus response information governance hub

Find out how NHS Digital is using your data in its work to support the government response to coronavirus (COVID-19).



科學研究作為科技防疫的一環

Coronavirus (COVID-19) response transparency notice

We are undertaking a range of work to support the government response to the coronavirus outbreak. This notice details our legal bases for processing personal data in the course of this work.

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[Types of personal data we process](#)

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[Who we share your data with](#)

[How long we keep your personal data for](#)

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[Your rights over your personal data and further information](#)

Types of organisations we may share your data with

The types of organisations we may share your data with include:

- the [Department of Health and Social Care](#) and other government departments, as part of the government response to coronavirus
- [NHS England](#)
- [Public Health England](#)
- GPs
- Clinical Commissioning Groups
- Local Authorities
- other NHS, health, or social care organisations
- NHS bodies in Scotland, Wales and Northern Ireland
- researchers involved in COVID-19 studies, such as university researchers, hospital researchers, pharmaceutical companies (for example, those who have developed a new vaccine), or clinical research organisations (private companies that help to run clinical trials)

We may also share your information with organisations who process personal data for us on our behalf. They are called Processors. Where we use Processors we have contracts in place with them which means that they can only process your personal data on our instructions. Our Processors are also required to comply with stringent security requirements when processing your personal data on our behalf.

We will also publish data we have obtained for COVID-19 purposes which is anonymous, so that no individuals can be identified from that data. This will enable NHS and other organisations to use this anonymous data for statistical analysis and for planning, commissioning and research purposes as part of the response to coronavirus.



科學研究作為科技防疫的一環

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researchers involved in COVID-19 studies, such as university researchers, hospital researchers, pharmaceutical companies (for example, those who have developed a new vaccine), or clinical research organisations (private companies that help to run clinical trials)



科學研究作為科技防疫的一環

General Practice Data for Planning and Research (GPDPR)

NHS Digital's daily collection of GP data will support vital health and care planning and research.

What the data will be used for

Patient data collected from general practice is needed to support a wide variety of research and analysis to help run and improve health and care services. Whilst the data collected in other care settings such as hospitals is valuable in understanding and improving specific services, it is the patient data in general practice that helps us to understand whether the health and care system as a whole is working for patients.

In addition to replacing what GPES already does, the General Practice Data for Planning and Research service will also help to support the planning and commissioning of health and care services, the development of health and care policy, public health monitoring and interventions (including coronavirus (COVID-19) and enable many different areas of research, for example:

1. Research the long-term impact of coronavirus on the population

There is a lot about coronavirus that we do not know, including the long-term health impacts. Patient data from GP medical records will be very important in the coming months and years, as scientists analyse and understand the impact of the virus on human health.

2. Analyse healthcare inequalities

For example, to understand how people of different ethnicities access healthcare and how the outcomes of particular groups compare to the rest of the population. This will help the NHS to assess healthcare inequalities and make any necessary changes to its services.

3. Research and develop cures for serious illnesses

For example, patient data is being used by the [University of Oxford RECOVERY trial](#), which has found ways to improve the treatment for people with coronavirus.

Researchers have previously used patient data from GP medical records to show that there was no association between the [measles, mumps and rubella vaccine and the development of autism](#); to confirm the safety of the [meningococcal group B vaccine](#); and to investigate whether certain [medications increase the risk of cancer](#).



科學研究作為科技防疫的一環

General Practice Data for Planning and Research (GPDPR)

NHS Digital's daily collection of GP data will support vital health and care planning and research.

NHS Digital will collect:

- ✓ data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments, including information about physical, mental and sexual health
- ✓ data on sex, ethnicity and sexual orientation
- ✓ data about staff who have treated patients

NHS Digital does not collect:

- ✗ name and address (except for postcode, protected in a unique coded form)
- ✗ written notes (free text), such as the details of conversations with doctors and nurses
- ✗ images, letters and documents
- ✗ coded data that is not needed due to its age - for example medication, referral and appointment data that is over 10 years old
- ✗ coded data that GPs are not permitted to share by law - for example certain codes about IVF treatment, and certain information about gender re-assignment



科學研究作為科技防疫的一環

General Practice Data for Planning and Research (GPDPR)

NHS Digital's daily collection of GP data will support vital health and care planning and research.

Opting out

If you don't want your identifiable patient data to be shared for purposes except for your own care, you can opt-out by registering a [Type 1 Opt-out](#) or a [National Data Opt-out](#), or both. These opt-outs are different and they are explained in more detail below. Your individual care will not be affected if you opt-out using either option.

Type 1 Opt-out (opting out of NHS Digital collecting your data)

We will not collect data from GP practices about patients who have registered a Type 1 Opt-out with their practice. More information about Type 1 Opt-outs is in our [GP Data for Planning and Research Transparency Notice](#), including a form that you can complete and send to your GP practice.



ARTICLE General Practice Data for Planning and Research: NHS Digital Transparency Notice

How and why NHS Digital collects, analyses, publishes and shares data collected from GP practices for planning and research.



If you register a Type 1 Opt-out after this collection has started, no more of your data will be shared with us.

If you do not want NHS Digital to share your identifiable patient data with anyone else for purposes beyond your own care, then you can also register a [National Data Opt-out](#).

National Data Opt-out (opting out of NHS Digital sharing your data)

We will collect data from GP medical records about patients who have registered a National Data Opt-out. The National Data Opt-out applies to identifiable patient data about your health, which is called confidential patient information.

NHS Digital won't share any confidential patient information about you - this includes GP data, or other data we hold, such as hospital data - with other organisations, unless there is an exemption to this.

To find out more information and how to register a National Data Opt-Out, please read our [GP Data for Planning and Research Transparency Notice](#).



科學研究作為科技防疫的一環

General Practice Data for Planning and Research (GPDPR)

NHS Digital's daily collection of GP data will support vital health and care planning and research.

Withdrawal of Data Provision Notice

Further to the announcement made 8 June, the implementation of GP Data for Planning and Research has been deferred to provide more time to speak with patients, doctors, health charities and others.

The Data Provision Notice has, therefore, been withdrawn and no action is required by GP practices or GP system suppliers in response to it.



資料治理作為資料應用的核心

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- 為何喊停？
 - 缺乏信任
 - 為何缺乏信任？
 - 不夠透明
 - 為何不夠透明？
 - 沒有明確規範
 - 為何沒有明確規範？
 - 法學院的問題，問我們醫學院/公衛學院咧...



資料治理作為資料應用的核心

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- 資料治理作為解方
 - 公部門資料再利用
 - 資料分享
 - 資料利他：尤其針對以資料為（生醫）科學研究與應用
 - 3. 同意程序在實務上之操作困境
- 無法那麼猴急



資料治理作為資料應用的核心

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□ 釋字603號解釋

- 主管機關尤應配合當代科技發展，運用足以確保資訊正確及安全之方式為之，並對所蒐集之指紋檔案採取組織上與程序上必要之防護措施，以符憲法保障人民資訊隱私權之本旨。



資料治理作為資料應用的核心

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□ 釋字603號解釋

- 辨明(identify)現在究竟是以那兩個利益作為平衡之標的：
 - ✓ 資訊隱私與個人資料保護權利標的之利益
 - ✓ 「享有科技進步及其應用所得利益之權利 (the right to enjoy the benefits of scientific progress and its applications)」所保護之對象



資料治理作為資料應用的核心

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□ 釋字603號解釋

- ▶ 重新建構一個可行且具一致性的權利衡平架構：
 1. 將資料蒐集最小化原則依據科技之發展，做出較為**寬鬆**而**具有彈性**的詮釋
 2. 無論寬鬆與否，所應依循之基礎價值毋寧應當聚焦於社會群體與個人對於該等（防疫）科學研究之**信任**



資料治理作為資料應用的核心

□ 民主科技治理的監控：

□ 制度設計

- 法律保留
- 干預基本權越深，越需特定與明確相關規則

□ 組織監理



資料治理作為資料應用的核心

- 資料治理第一要務：信任
 - 風險治理：
 - DPIA
 - 風險揭露/告知
 - 自動化做成決策/演算法
 - 透明：
 - 去識別化/匿名化
 - 資訊流
 - 資訊安全
 - 持續性監理



資料治理作為資料應用的核心

- 以個資保護為核心的資料法制
 - 資訊隔離的「穀倉(silo)」
 - 降低了導致「火燒連環船」式的連鎖個資風險
 - 資料利用的FAIR原則



資料治理作為資料應用的核心

- 台灣的法制問題
 - 沒有法制…
 - 開放政府資料（有政策、指引、規則）
 - 個別領域的個資規範
- 台灣的組織問題
 - 沒有組織：個資保護/資料監管之專責機關



公部門資料釋出再利用：科學研究

- 資料可攜權
 - 台灣沒有
 - 歐盟說不夠
 - 將資料攜出之權利(the right to export data)
 - 請求個資控管人直接傳輸個資予第三人之權利(the right to directly transfer data)
 - 難題：
 - 同意好困難
 - 個資當事人欠缺個資權利（專業）知識
 - 推斷型資料之資料再利用與共享之原則禁止
 - 不得基於公共利益目的而為資料再利用與共享



公部門資料釋出再利用：科學研究

□ 資料可攜權

- 不得基於**公共利益**目的而為**資料再利用與共享**
 - 依GDPR第20(3)條之規定，資料可攜權不適用於資料控管人基於公共利益而執行職務或行使公權力所必要之情狀。
 - 其立法之思考脈絡乃是在私部門之資料可攜在目的上所期待強化之個人資料控制權能，是因為在**私部門間資料傳輸具有競爭的市場機制**，因此需要藉由資料可攜權來強化該等控制權能以保障在競爭市場上的個人權利(lock-in effect)。
 - 但相對地如果資料控制者為公務機關，則其所蒐集、處理與利用個資之行為均可能是出於公益目的如執行法律及基於公共行政本旨，但前述理據在公部門處理個資乃是基於基於公共利益而執行職務或行使公權力所必須的行為時則不存在，因此排除之。



公部門資料釋出再利用：科學研究

□ 資料再利用之明確法規範

□ 台灣沒有

□ 歐盟說不夠

- 在實務上對於包含有資料控制人或第三人之其他權利難以就該等資料再利用
- 但是，如果在具有**明確的公共利益**且經**利益權衡**後確有必要，或當事人同意之情狀發生時，前揭包含有其他非個資當事人權利之資料非必不得再為利用。



公部門資料釋出再利用：科學研究

資料再利用之明確法規範

台灣沒有

歐盟說不夠

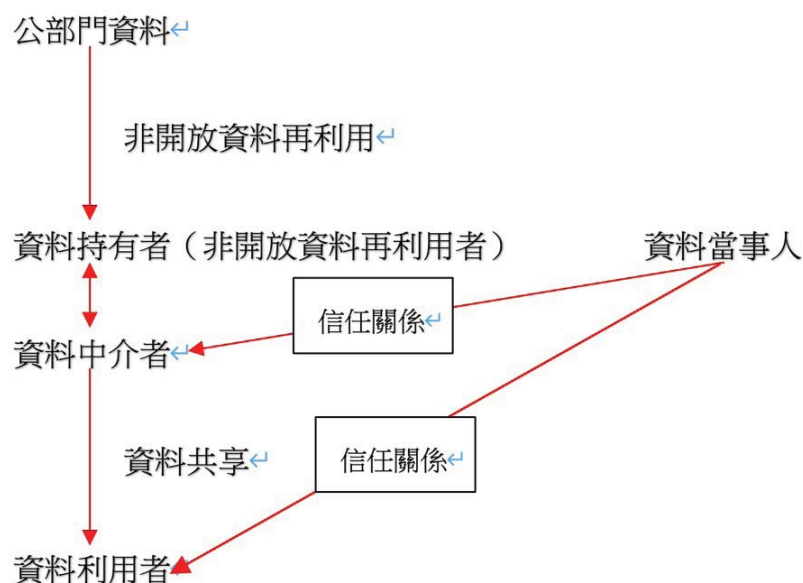
要件上必須至少包括須為非歧視性、合比例性、對於資料種類與再利用資料本質即在利用目的間具客觀合理關聯性，以及不限制競爭之原則。

對於公部門本身之責任，此間無論何者均須符合比例原則之要求：不要搞死機關！



資料共享

資料中介者



圖二：資訊受託人概念下資料中介者的資訊共享



資料共享

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資料是門好生意： APPLE v FACEBOOK



資料共享

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資料是門好生意： APPLE v FACEBOOK



< 隱私權 追蹤

允許 App 發出追蹤請求

允許 App 請求許可來追蹤您在其他公司 App 和網站中的活動。關閉此設定時，會自動拒絕所有新的 App 追蹤請求。 [更多內容...](#)

之前要求透過識別碼追蹤您的活動的 App 會顯示在此處。系統會對您已拒絕權限的 App 阻擋其追蹤活動。

完成

追蹤

Apple 要求 App 開發者必須請求許可，才能在不屬於他們的 App 或網站上追蹤您的活動，以提供定向廣告，測量您在接收廣告後的動作，或與資料仲介分享您的資料。

若您允許您的活動被追蹤，App 可以透過 App 收集有關您或您的裝置資訊（例如使用者或裝置識別碼、目前裝置的「廣告識別碼」、您的姓名、電子郵件地址或您曾提供的其他識別資料），將這些資料與第三方或第三方 App、網站或內容收集有關您或您的裝置資訊結合。此結合資訊可用來進行定向廣告或廣告測量。App 開發者可能會選擇與資料仲介分享資訊，這可能會連結到有關您或您裝置的公開和其他資訊。

若您拒絕 App 追蹤您的活動，App 將無法取用您裝置的「廣告識別碼」（之前可透過裝置上的「限制廣告追蹤」設定來控制）。App 開

□ APPLE v FACEBOOK



資料利他

- 資料利他之明確法規範
 - ▣ 台灣沒有
 - ▣ 歐盟說不夠
 - 「**公共利益**」的不確定法律概念
 - 「無從識別」在科學技術上難以真正實現
 - 同意程序在實務上之操作困境

資料利他

□ 資料利他之明確法規範

□ 台灣沒有

□ 歐盟說不夠

- 在GDPR前言第50點中本即指出個資處理之目的非基於原蒐集該等個資之目的者，於新處理及原蒐集之目的得相互兼容者，亦得為之。
- 英國DPA 2018為例，如果個資處理的目的隨時間而改變，或者控管者想將資料用於其原本未曾預設之新目的，則控管者僅能在以下情況下進行：
 - 新目的與原始目的兼容；
 - 新的目的獲得當事人的特定同意；
 - 依據明確的法律規定，而該規定要求或允許出於公共利益的目的是進行新的處理，例如公共機構的新功能等。



資料利他

□ 資料利他之明確法規範

□ 台灣沒有

□ 歐盟說不夠

- 信任擔保條件：
 - 透明原則
 - 通知義務
 - 目的特定：須為公共利益
 - 同意：處理資料行為須特定管轄法院
 - 資料安全
 - 監管機制
 - 提供有效率的同意機制



資料利他

- 資料利他之組織規範
 - 資料利他組織
 - 法人組織
 - 公益性質：非營利（但可收取手續費用）
 - 登記制度
 - 須以法律上獨立架構從事資料利他行為，而與其他前行為分離



結論

- 事實上沒有不可以
- 是因為法律規範不夠，而不是過多，而導致了基於不理解之焦慮
- 數位發展部願景之一：資料治理
- 個資專責主管（監管）機關



謝謝聆聽



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