資料治理概念下的健康資料個資應用與界線：
以英國為觀察對象

翁逸泓

Associate Professor,
College of Law,
Shih Hsin University, Taiwan

July, 2022

中央研究院法律學研究所

前言

- **大綱**
  - 科學研究作為科技防疫的一環
  - 健康（保）資料作為科學研究的一環
  - **UK Data Reform Proposals (?)**
  - 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
  - 資料共享與資料利他

科學研究作為科技防疫的一環

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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1. COVID-19 Infection Survey
2. Study design: sampling
3. Study design: data we collect
4. Processing the data
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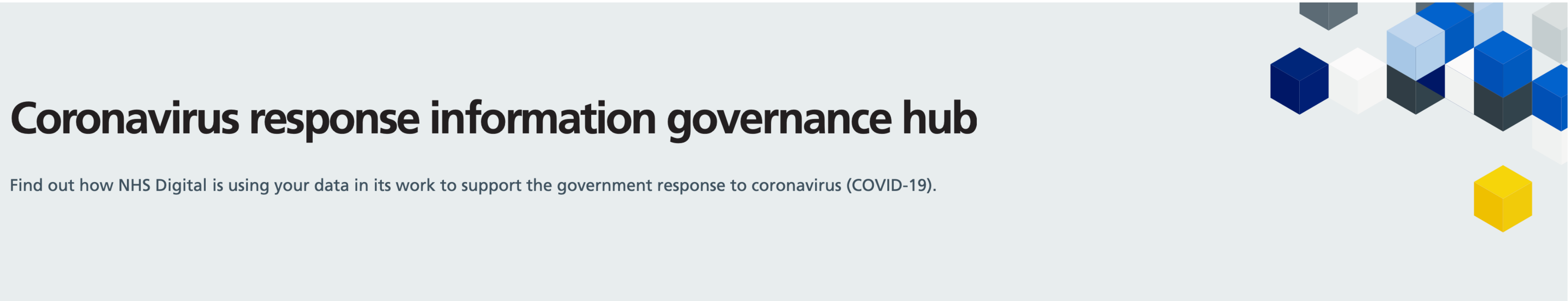
7. Positivity rates
8. Incidence
9. Antibody and vaccination estimates
10. Weighting
11. Confidence intervals and credible intervals
12. Statistical testing
13. Geographic coverage
14. Analysis feeding into R
15. Uncertainty in the data

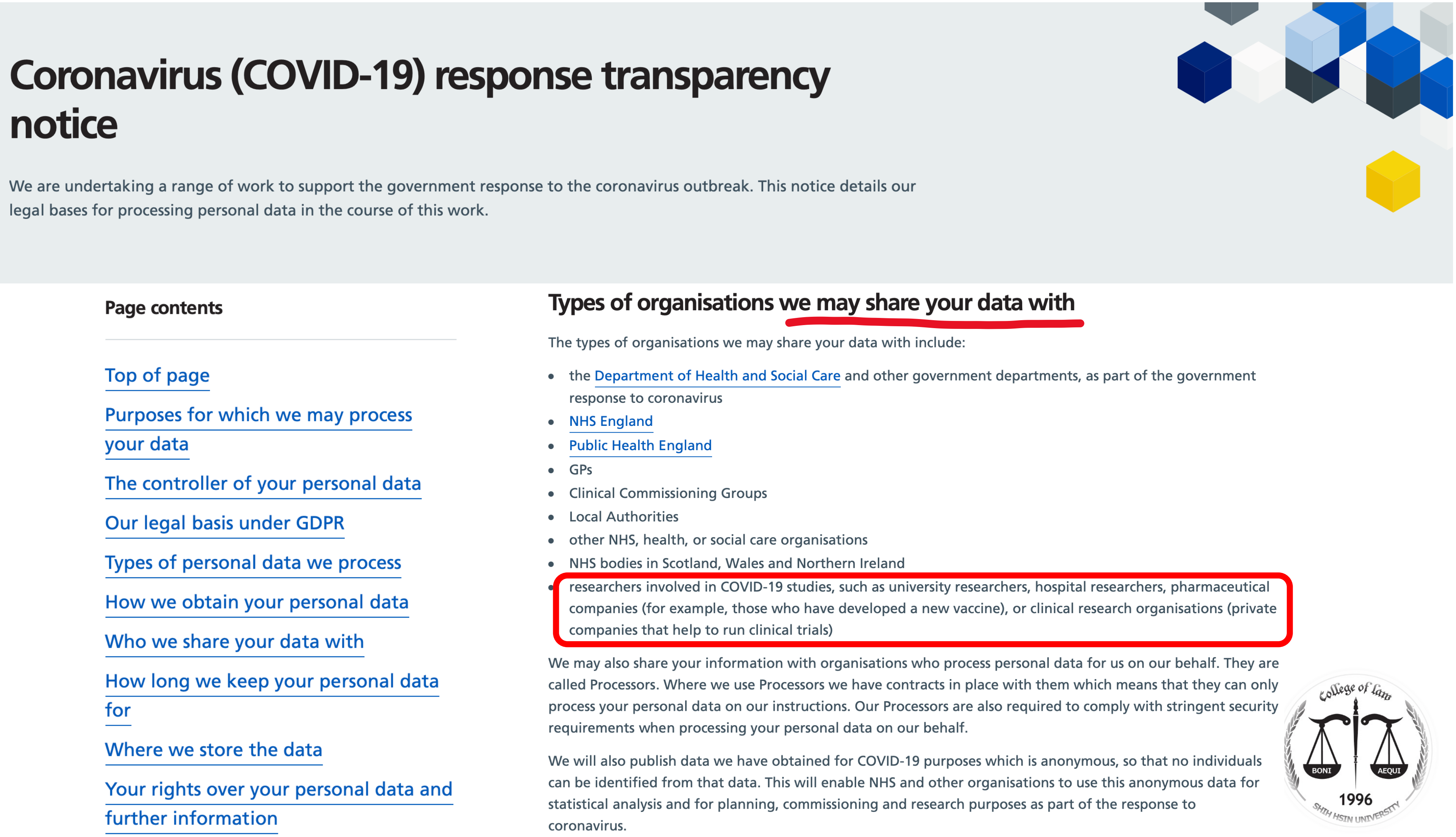
科學研究作為科技防疫的一環



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.

Page contents

Types of organisations we may share your data with

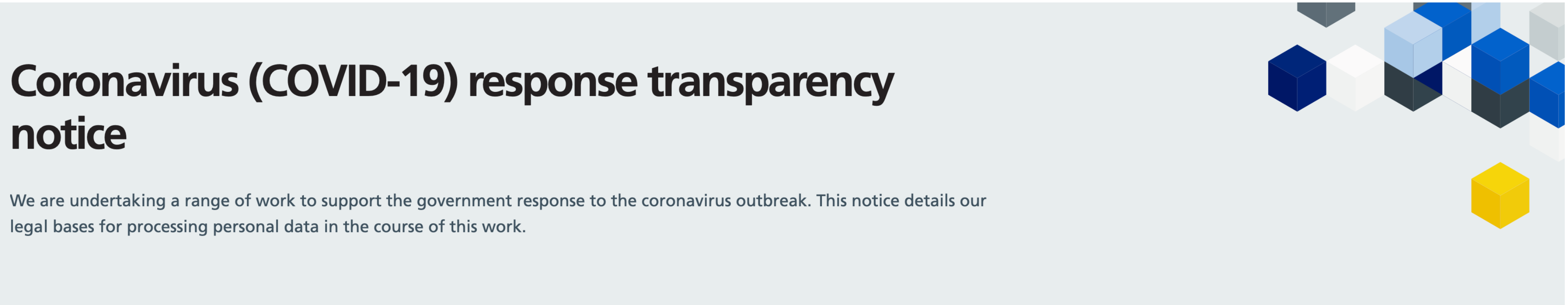
The types of organisations we may share your data with include:

- 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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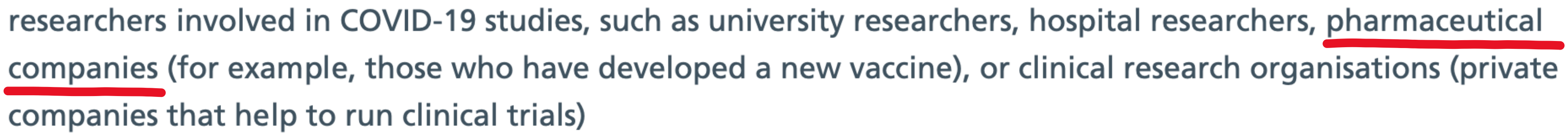


researchers involved in COVID-19 studies, such as university researchers, hospital researchers, pharmaceutical companies (for example, those who have developed a new vaccine), or clinical research organisations (private companies that help to run clinical trials)

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

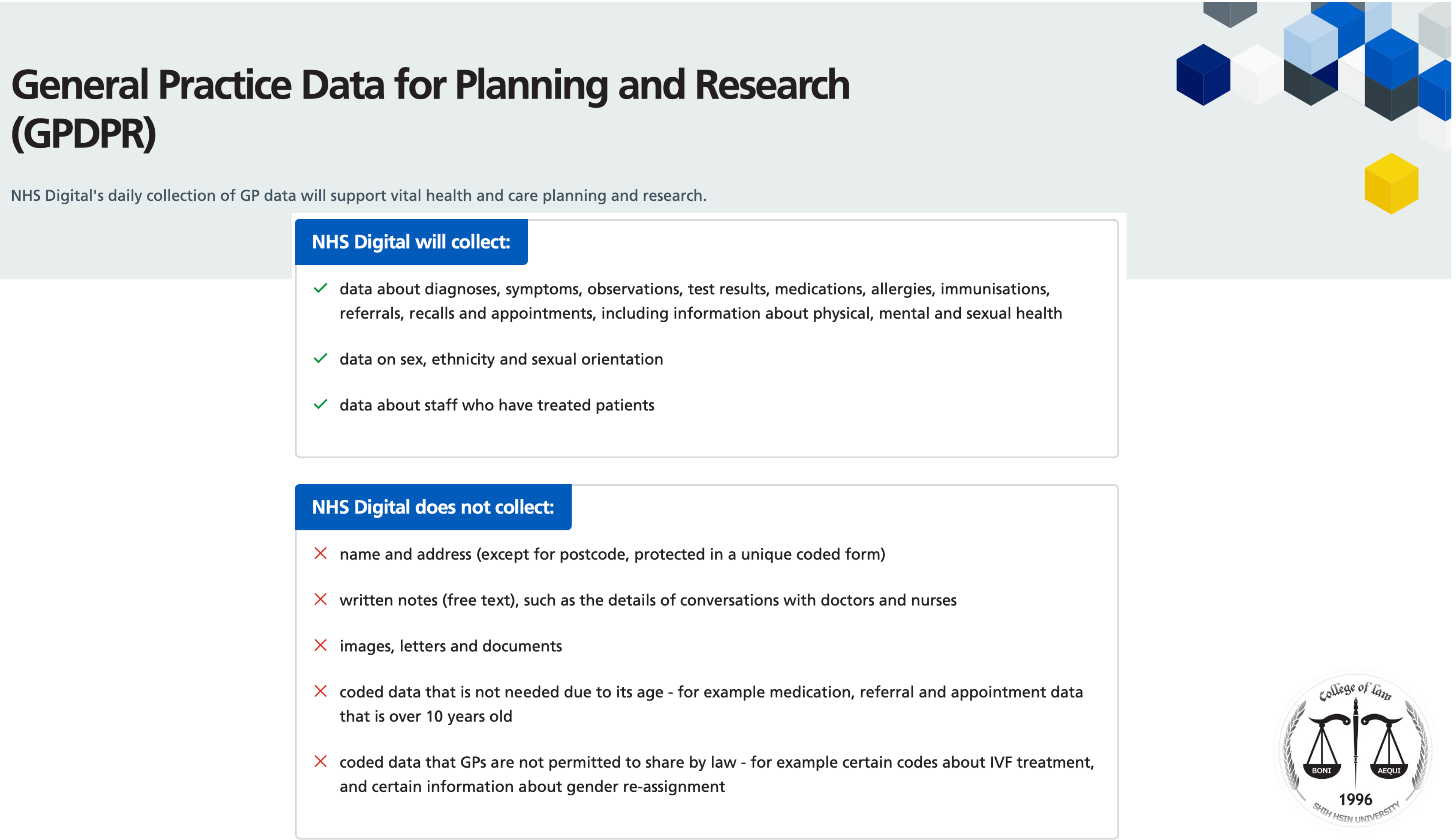
For example, to understand how people of different ethnicities access healthcare and how the outcomes of particular groups compare to the rest of the population. This will help the NHS to assess healthcare inequalities and make any necessary changes to its services.

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.

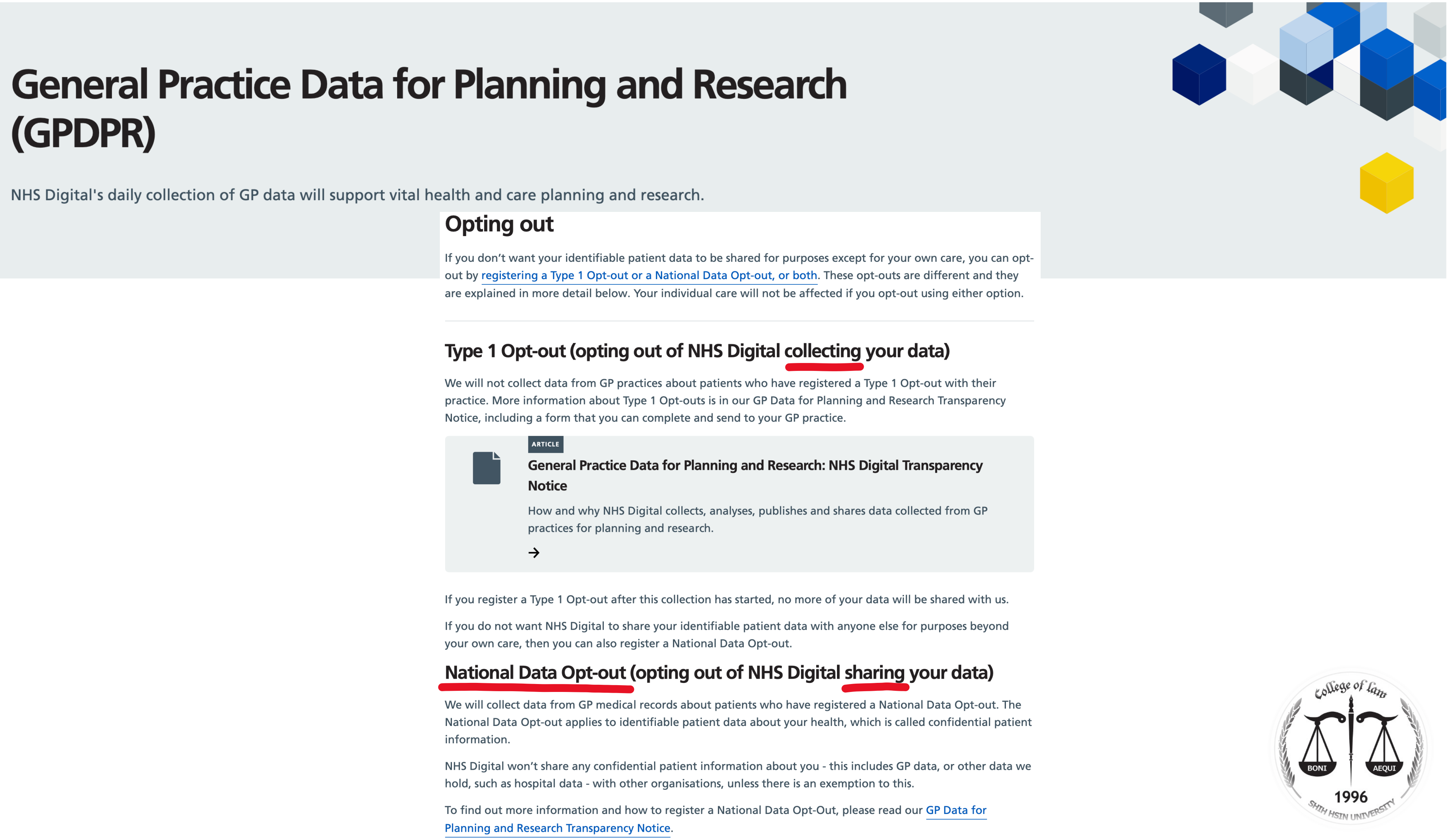
NHS Digital will collect:

- ✓ 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.

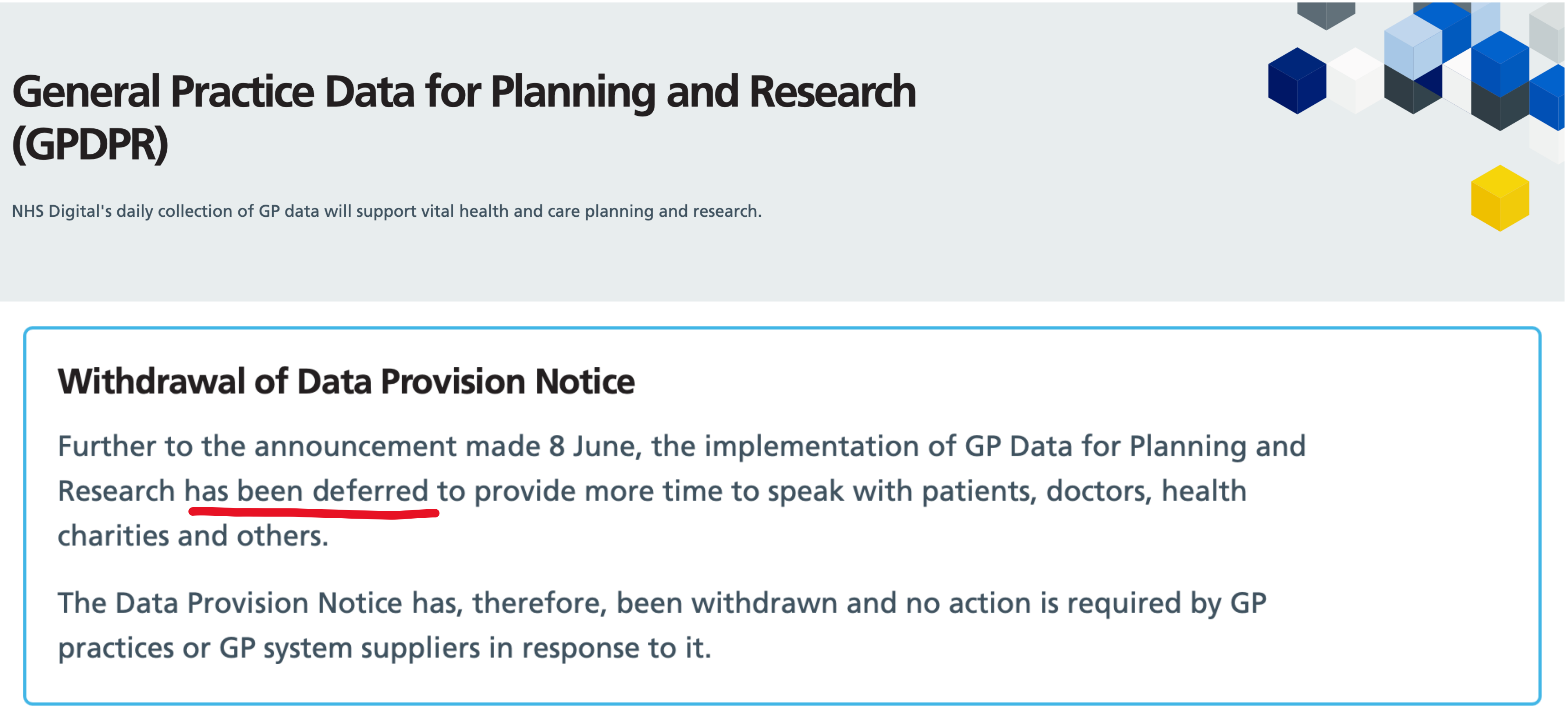
National Data Opt-out (opting out of NHS Digital sharing your data)

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)

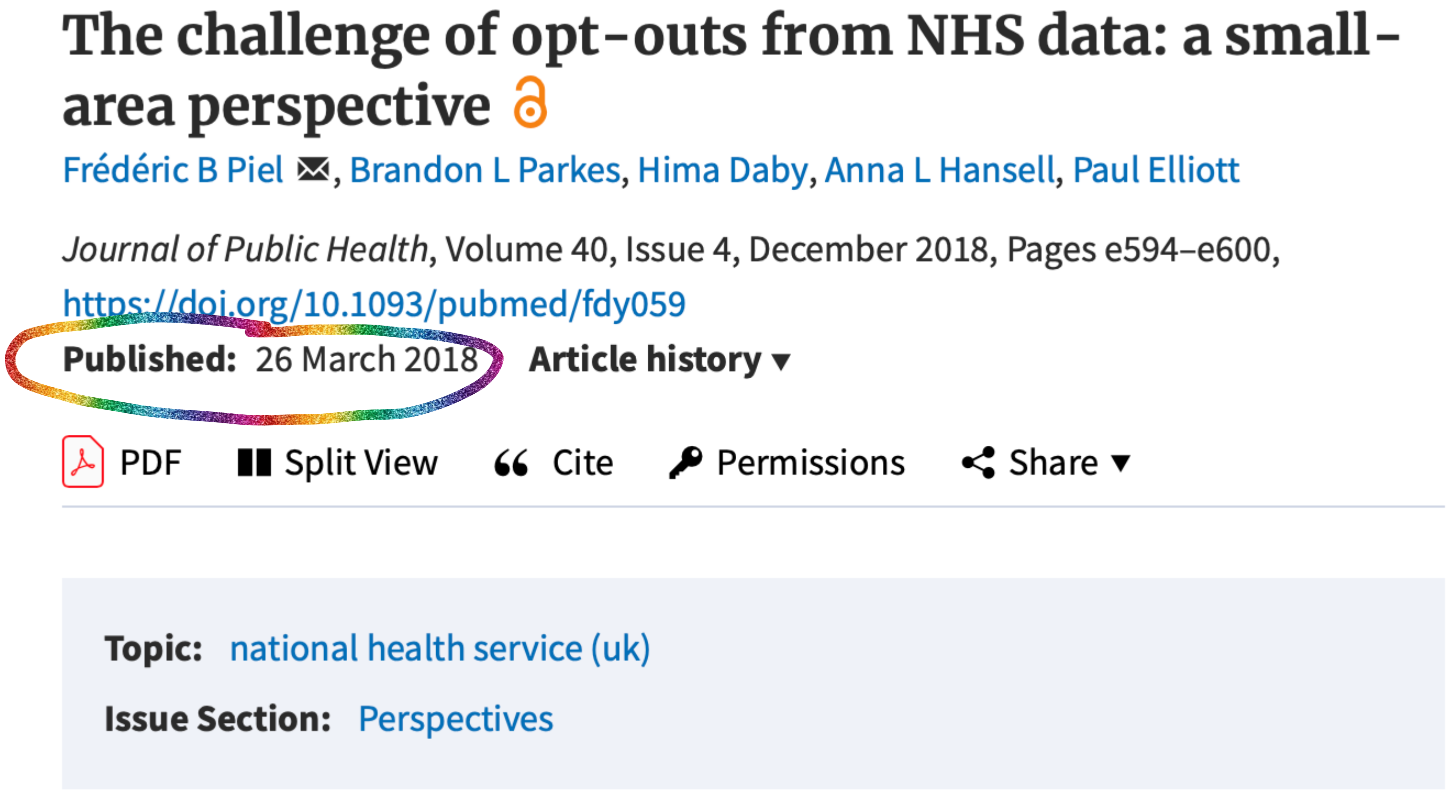
NHS Digital's daily collection of GP data will support vital health and care planning and research.

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.

健康（保）資料作為科學研究的一環



The challenge of opt-outs from NHS data: a small-area perspective

Frédéric B Piel ✉, Brandon L Parkes, Hima Daby, Anna L Hansell, Paul Elliott

Journal of Public Health, Volume 40, Issue 4, December 2018, Pages e594–e600, https://doi.org/10.1093/pubmed/fdy059

Published: 26 March 2018

Topic: national health service (uk)

Issue Section: Perspectives

健康（保）資料作為科學研究的一環

會台字第13769號
言詞辯論意旨

衛生福利部

無條件任意退出權的影響(一)

退出權應予保障，但無條件任意退出權，所造成的公衛風險為何？

1) 2005年David Armstrong教授（65 Archives Internal Med. 1125)研究：

   即使拒絕率低至3.2%，仍有可能因資料偏差而誤醫。

2) 英國NHS資料庫實施退出權後，退出者約占4.97%。

健康（保）資料作為科學研究的一環

The Observer
NHS

This article is more than **10 months old**

NHS data grab on hold as millions opt out

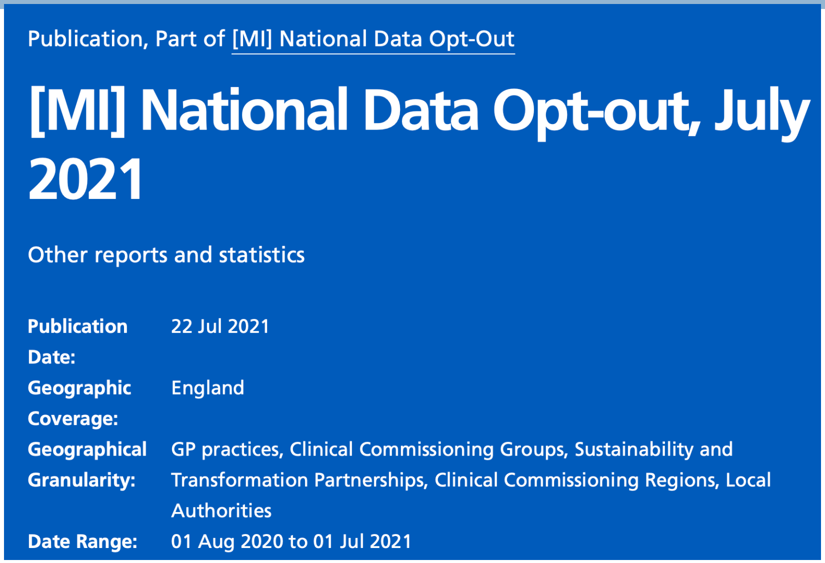
A plan to share GP data was set to launch in September, but an online summer campaign has prompted widespread dissent

Chaminda Jayanetti

Sun 22 Aug 2021 08.15 BST

'We want to see promises delivered' – privacy campaigner Phil Booth of medConfidential.

健康（保）資料作為科學研究的一環



Publication, Part of [MI] National Data Opt-Out

[MI] National Data Opt-out, July 2021

Other reports and statistics

Publication Date: 22 Jul 2021
Geographic Coverage: England
Geographical Granularity: GP practices, Clinical Commissioning Groups, Sustainability and Transformation Partnerships, Clinical Commissioning Regions, Local Authorities
Date Range: 01 Aug 2020 to 01 Jul 2021

There were 3,032,917 national data opt-outs as at 1st July 2021, an increase of 1,275,153 compared to 1 June 2021.

As at 1 July 2021 4.97 per cent of the population registered with a GP practice have a national data opt-out, an increase of 2.08 percentage points compared to 1 June 2021.

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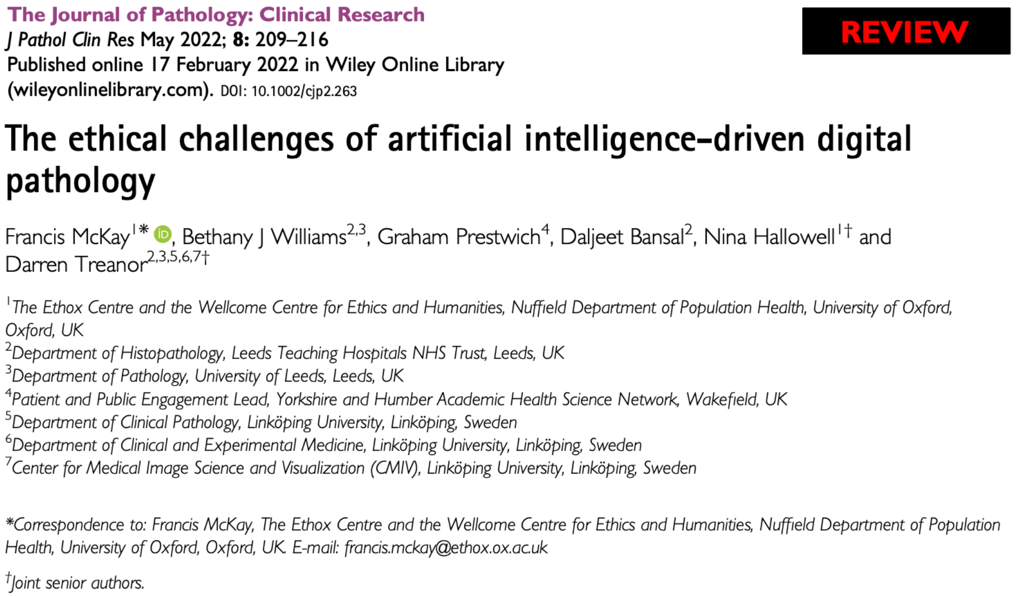

The Journal of Pathology: Clinical Research
J Pathol Clin Res May 2022; **8:** 209–216
Published online 17 February 2022 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/cjp2.263

REVIEW

The ethical challenges of artificial intelligence-driven digital pathology

Francis McKay[1]*, Bethany J Williams[2,3], Graham Prestwich[4], Daljeet Bansal[2], Nina Hallowell[1]† and Darren Treanor[2,3,5,6,7]†

[1] *The Ethox Centre and the Wellcome Centre for Ethics and Humanities, Nuffield Department of Population Health, University of Oxford, Oxford, UK*
[2] *Department of Histopathology, Leeds Teaching Hospitals NHS Trust, Leeds, UK*
[3] *Department of Pathology, University of Leeds, Leeds, UK*
[4] *Patient and Public Engagement Lead, Yorkshire and Humber Academic Health Science Network, Wakefield, UK*
[5] *Department of Clinical Pathology, Linköping University, Linköping, Sweden*
[6] *Department of Clinical and Experimental Medicine, Linköping University, Linköping, Sweden*
[7] *Center for Medical Image Science and Visualization (CMIV), Linköping University, Linköping, Sweden*

**Correspondence to: Francis McKay, The Ethox Centre and the Wellcome Centre for Ethics and Humanities, Nuffield Department of Population Health, University of Oxford, Oxford, UK. E-mail: francis.mckay@ethox.ox.ac.uk*

†Joint senior authors.

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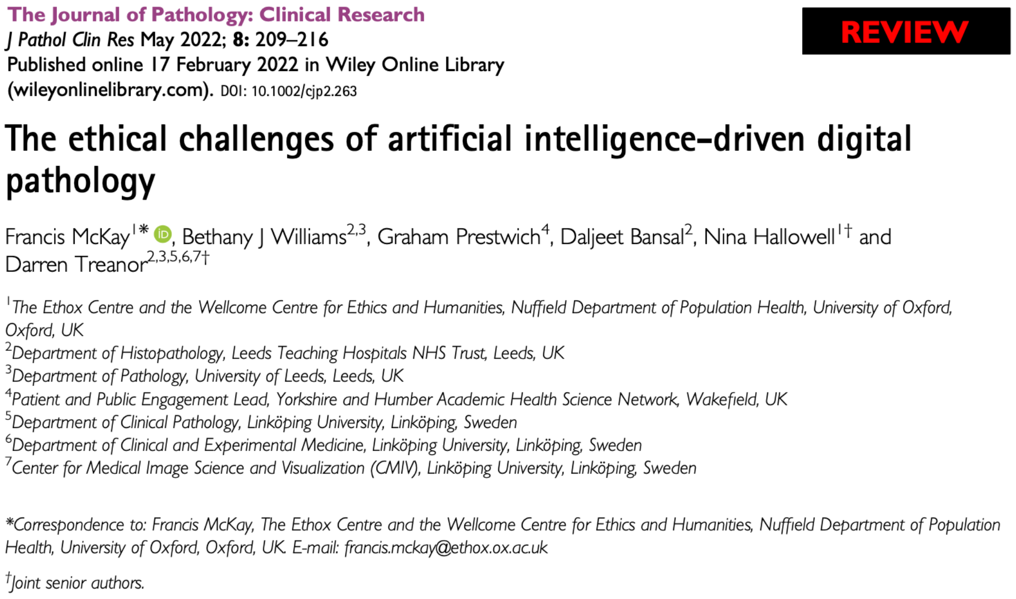

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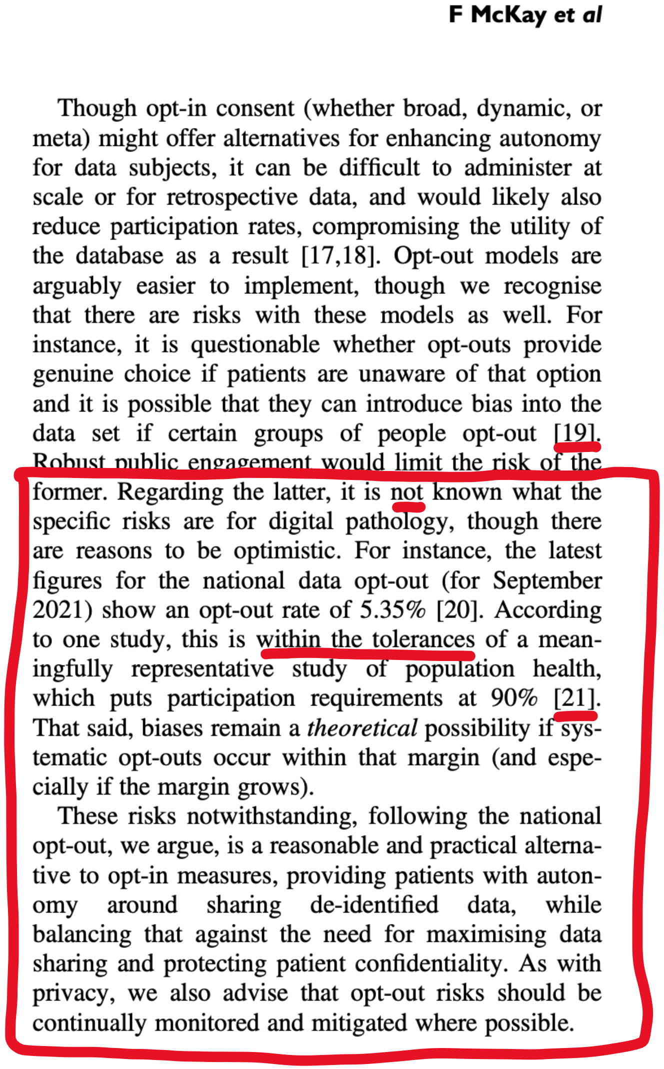
健康（保）資料作為科學研究的一環



F McKay *et al*

Though opt-in consent (whether broad, dynamic, or meta) might offer alternatives for enhancing autonomy for data subjects, it can be difficult to administer at scale or for retrospective data, and would likely also reduce participation rates, compromising the utility of the database as a result [17,18]. Opt-out models are arguably easier to implement, though we recognise that there are risks with these models as well. For instance, it is questionable whether opt-outs provide genuine choice if patients are unaware of that option and it is possible that they can introduce bias into the data set if certain groups of people opt-out [19]. Robust public engagement would limit the risk of the former. Regarding the latter, it is not known what the specific risks are for digital pathology, though there are reasons to be optimistic. For instance, the latest figures for the national data opt-out (for September 2021) show an opt-out rate of 5.35% [20]. According to one study, this is within the tolerances of a meaningfully representative study of population health, which puts participation requirements at 90% [21]. That said, biases remain a *theoretical* possibility if systematic opt-outs occur within that margin (and especially if the margin grows).

These risks notwithstanding, following the national opt-out, we argue, is a reasonable and practical alternative to opt-in measures, providing patients with autonomy around sharing de-identified data, while balancing that against the need for maximising data sharing and protecting patient confidentiality. As with privacy, we also advise that opt-out risks should be continually monitored and mitigated where possible.

即便是顯著的5.35%退出率：

1. 無特別危險
2. 情況仍然樂觀
3. 科學研究指出，此係在可容忍的範圍之內！
4. 學者甚至認為opt-in模式似乎更好！

UK Data Reform Proposals (?)

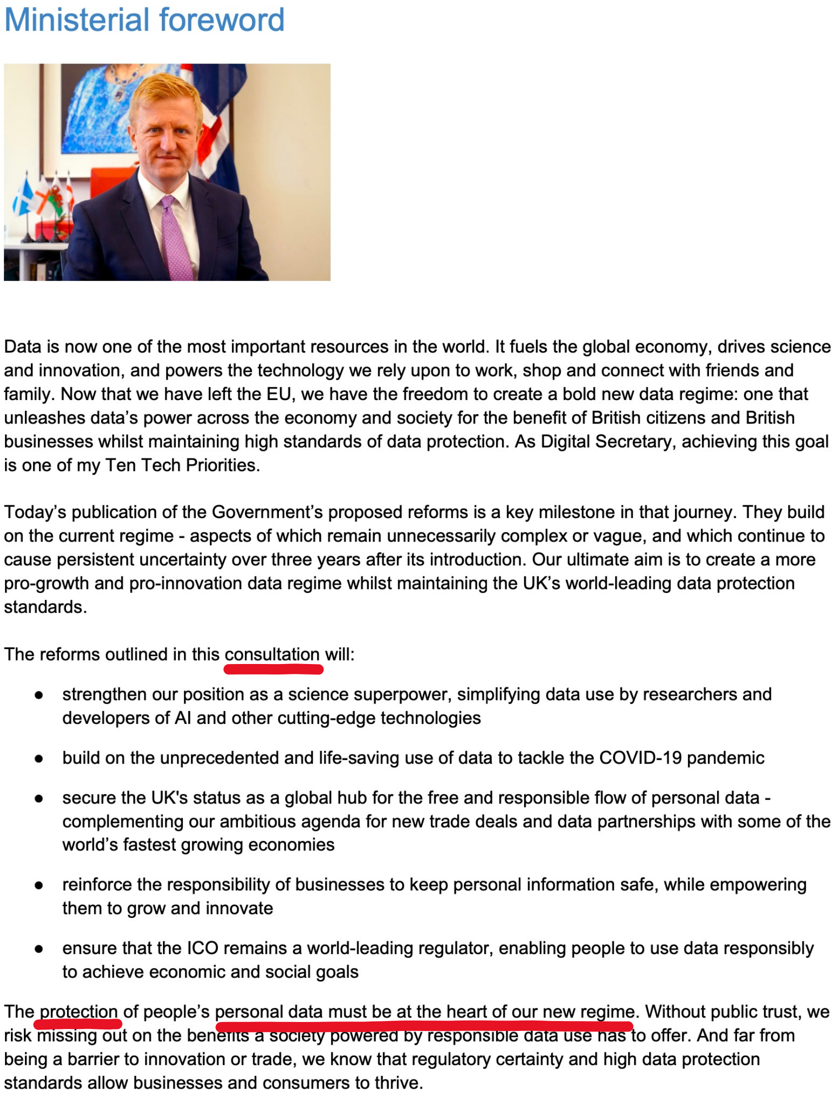
- 英國脫歐後，對於資料應用之管制轉向了嗎？！
    - **UK Data Reform Proposals (?)**

Department for
Digital, Culture
Media & Sport

Data: A new direction

10 September 2021

UK Data Reform Proposals (?)



Ministerial foreword

Data is now one of the most important resources in the world. It fuels the global economy, drives science and innovation, and powers the technology we rely upon to work, shop and connect with friends and family. Now that we have left the EU, we have the freedom to create a bold new data regime: one that unleashes data's power across the economy and society for the benefit of British citizens and British businesses whilst maintaining high standards of data protection. As Digital Secretary, achieving this goal is one of my Ten Tech Priorities.

Today's publication of the Government's proposed reforms is a key milestone in that journey. They build on the current regime - aspects of which remain unnecessarily complex or vague, and which continue to cause persistent uncertainty over three years after its introduction. Our ultimate aim is to create a more pro-growth and pro-innovation data regime whilst maintaining the UK's world-leading data protection standards.

The reforms outlined in this consultation will:

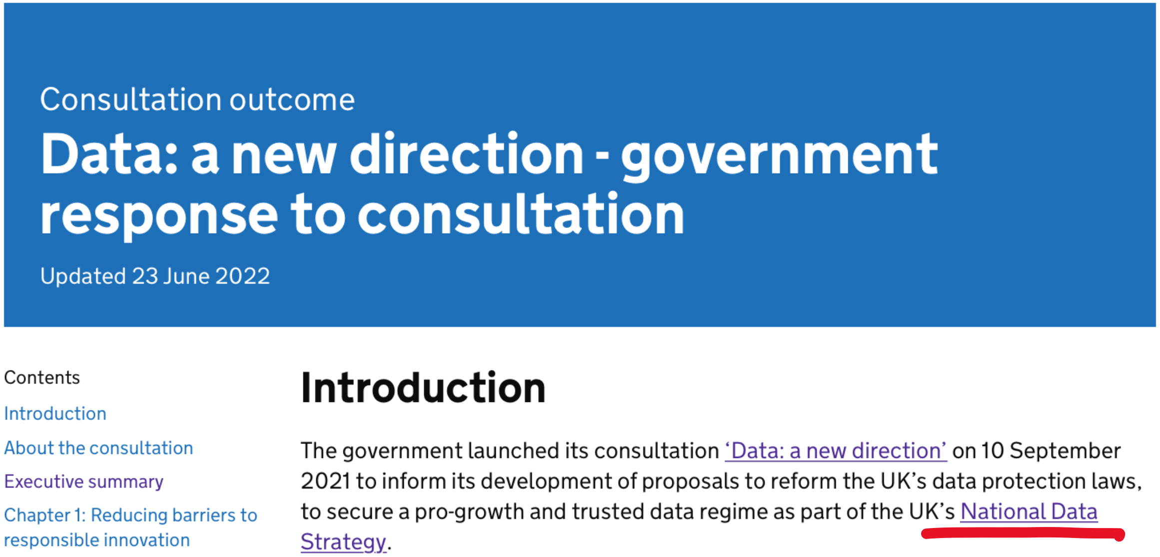
- strengthen our position as a science superpower, simplifying data use by researchers and developers of AI and other cutting-edge technologies
- build on the unprecedented and life-saving use of data to tackle the COVID-19 pandemic
- secure the UK's status as a global hub for the free and responsible flow of personal data - complementing our ambitious agenda for new trade deals and data partnerships with some of the world's fastest growing economies
- reinforce the responsibility of businesses to keep personal information safe, while empowering them to grow and innovate
- ensure that the ICO remains a world-leading regulator, enabling people to use data responsibly to achieve economic and social goals

The protection of people's personal data must be at the heart of our new regime. Without public trust, we risk missing out on the benefits a society powered by responsible data use has to offer. And far from being a barrier to innovation or trade, we know that regulatory certainty and high data protection standards allow businesses and consumers to thrive.

Chapter 1- Reducing barriers to responsible innovation

1.1 Introduction
1.2 Research Purposes
1.3 Further Processing
1.4 Legitimate Interests
1.5 AI and Machine Learning
1.6 Data Minimisation and Anonymisation
1.7 Innovative Data Sharing Solutions
1.8 Further Questions

UK Data Reform Proposals (?)



Consultation outcome

Data: a new direction - government response to consultation

Updated 23 June 2022

Introduction

The government launched its consultation 'Data: a new direction' on 10 September 2021 to inform its development of proposals to reform the UK's data protection laws, to secure a pro-growth and trusted data regime as part of the UK's National Data Strategy.

Policy paper

National Data Strategy

Updated 9 December 2020

UK Data Reform Proposals (?)

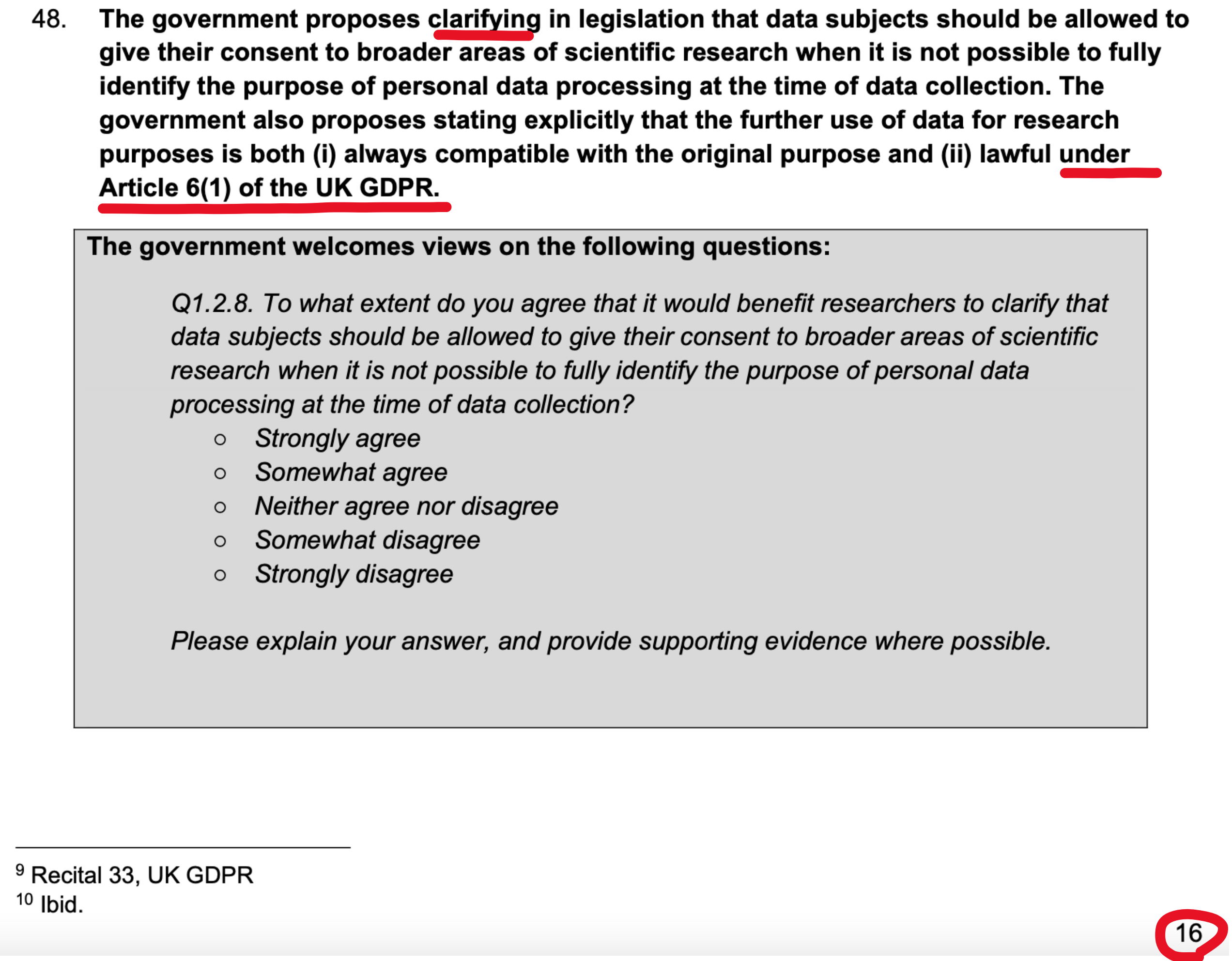
- **Use of Personal Data for Research Purposes**
  - The DCMS recognises that the current laws around the use of personal data for research purposes are complicated.
  - The proposed reforms focus on removing unnecessary hurdles to better enable researchers to unlock more personal data for responsible research uses.

UK Data Reform Proposals (?)

- **Use of Personal Data for Research Purposes**
  - Some of the proposals are:
    - Clarifying and creating more certainty around what "research purposes" means in practice;
    - Incorporating definitions of “scientific research”, “historical research” and “statistical purposes” into the legislation; and
    - Creating an exemption to the requirement to provide transparency information to data subjects when information is not obtained directly from the individual.

UK Data Reform Proposals (?)

Use of Personal Data for Research Purposes



48. The government proposes clarifying in legislation that data subjects should be allowed to give their consent to broader areas of scientific research when it is not possible to fully identify the purpose of personal data processing at the time of data collection. The government also proposes stating explicitly that the further use of data for research purposes is both (i) always compatible with the original purpose and (ii) lawful under Article 6(1) of the UK GDPR.

The government welcomes views on the following questions:

Q1.2.8. To what extent do you agree that it would benefit researchers to clarify that data subjects should be allowed to give their consent to broader areas of scientific research when it is not possible to fully identify the purpose of personal data processing at the time of data collection?

- ○ *Strongly agree*
- ○ *Somewhat agree*
- ○ *Neither agree nor disagree*
- ○ *Somewhat disagree*
- ○ *Strongly disagree*

Please explain your answer, and provide supporting evidence where possible.

---

[9] Recital 33, UK GDPR

[10] Ibid.

UK Data Reform Proposals (?)

- **Re-use/ further processing of Personal Data**
  - The DCMS plans to widen and clarify the circumstances in which data may be re-used and provide clarity on how organisations can better differentiate between new and further processing.

UK Data Reform Proposals (?)

- **Legitimate Interests**
  - Often businesses and organisations seek to rely on their legitimate business interests as the required legal basis for processing personal data.
  - In order to do so, under the UK GDPR, a balancing exercise must be undertaken weighing the business' legitimate interests against the rights of the relevant data subjects.

UK Data Reform Proposals (?)

- **Legitimate Interests**
  - The DCMS has recognised many organisations' concerns about the time and effort these legitimate interests impact assessments can take.
    - The DCMS proposes to introduce a limited, exhaustive list of legitimate interests for which organisations could use personal data without applying the legitimate interests balancing test.
    - The list is likely to include processing activities undertaken to prevent crime or report safeguarding concerns, or which are necessary for other important reasons of public interest.

UK Data Reform Proposals (?)

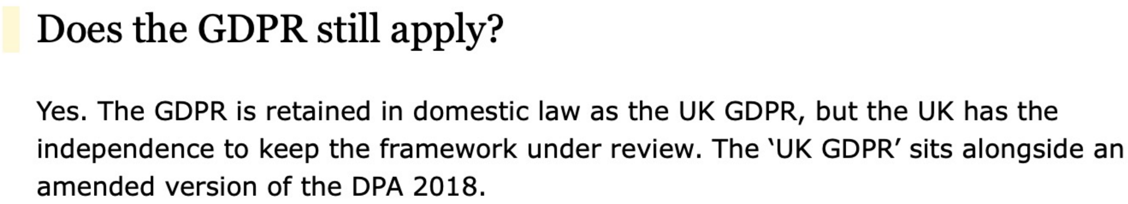
- **Innovative data sharing solutions**
  - This industry is nascent and the government sought views on its role in enabling the activity of **data intermediaries**.
  - A range of open questions were asked about what lawful grounds might be applicable to data intermediary activities, and conferring data protection processing rights and responsibilities to data intermediaries.

UK Data Reform Proposals (?)

- **Use of Personal Data for Research Purposes**

The Information Commissioner's Office

Draft guidance on the research provisions within the UK GDPR and the DPA 2018



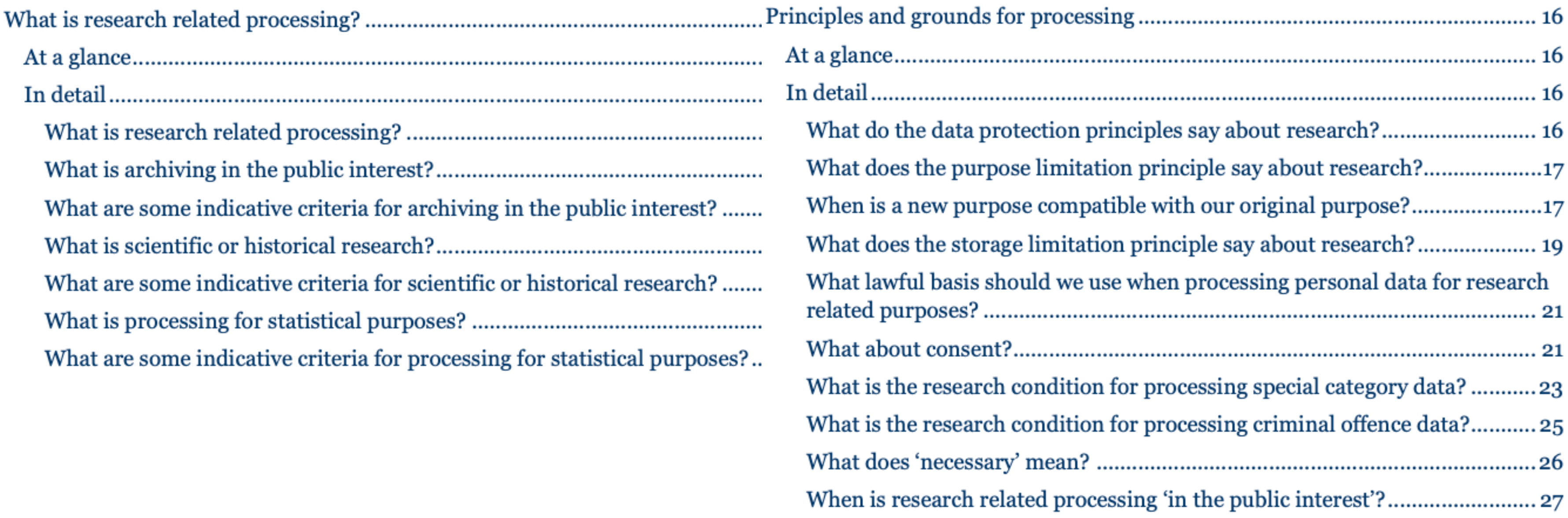
Does the GDPR still apply?

Yes. The GDPR is retained in domestic law as the UK GDPR, but the UK has the independence to keep the framework under review. The 'UK GDPR' sits alongside an amended version of the DPA 2018.

ico.

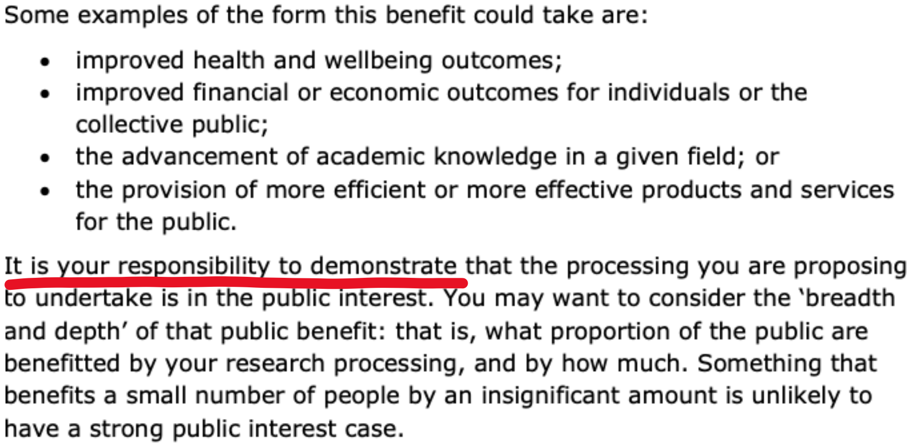
UK Data Reform Proposals (?)

- ☐ **Use of Personal Data for Research Purposes**



UK Data Reform Proposals (?)

- 法律制度要改革的條件
  - 有東西可以被改革
  - 更明確化：
    - 「科學研究」的定義
    - 公共利益的特定與舉證責任(ICO)



Some examples of the form this benefit could take are:

- improved health and wellbeing outcomes;
- improved financial or economic outcomes for individuals or the collective public;
- the advancement of academic knowledge in a given field; or
- the provision of more efficient or more effective products and services for the public.

It is your responsibility to demonstrate that the processing you are proposing to undertake is in the public interest. You may want to consider the 'breadth and depth' of that public benefit: that is, what proportion of the public are benefitted by your research processing, and by how much. Something that benefits a small number of people by an insignificant amount is unlikely to have a strong public interest case.

UK Data Reform Proposals (?)

- **法律制度要改革的條件**
  - 仍以個資保護作為核心
  - 資料治理概念的導入

資料治理作為資料應用的核心

- （英國）為何喊停？
  - **缺乏信任**
  - **為何缺乏信任？**
    - 不夠透明
    - 為何不夠透明？
      - 沒有關於健康資料應如何應用的明確規範
      - 為何沒有明確規範？
        - 這是法學院的問題，為什麼問醫學院/公衛學院咧？！
        - 問醫學院/公衛學院/電資學院/產業界的應該是要如何規範

資料治理作為資料應用的核心

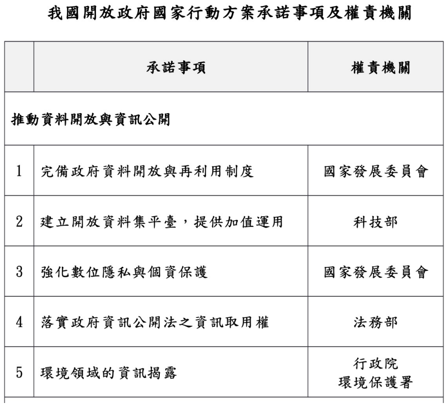
- 民主科技治理的監控：
  - 制度設計
    - 法律保留
    - 干預基本權越深，越需特定與明確相關規則
  - 組織監理

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（或是預先設計好的替代評估）
    - 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

- 台灣的法制問題
  - 沒有法制…
  - 開放政府資料（僅有政策、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
  - IRB？



我國開放政府國家行動方案承諾事項及權責機關

	承諾事項	權責機關
推動資料開放與資訊公開		
1	完備政府資料開放與再利用制度	國家發展委員會
2	建立開放資料集平臺，提供加值運用	科技部
3	強化數位隱私與個資保護	國家發展委員會
4	落實政府資訊公開法之資訊取用權	法務部
5	環境領域的資訊揭露	行政院 環境保護署

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

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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

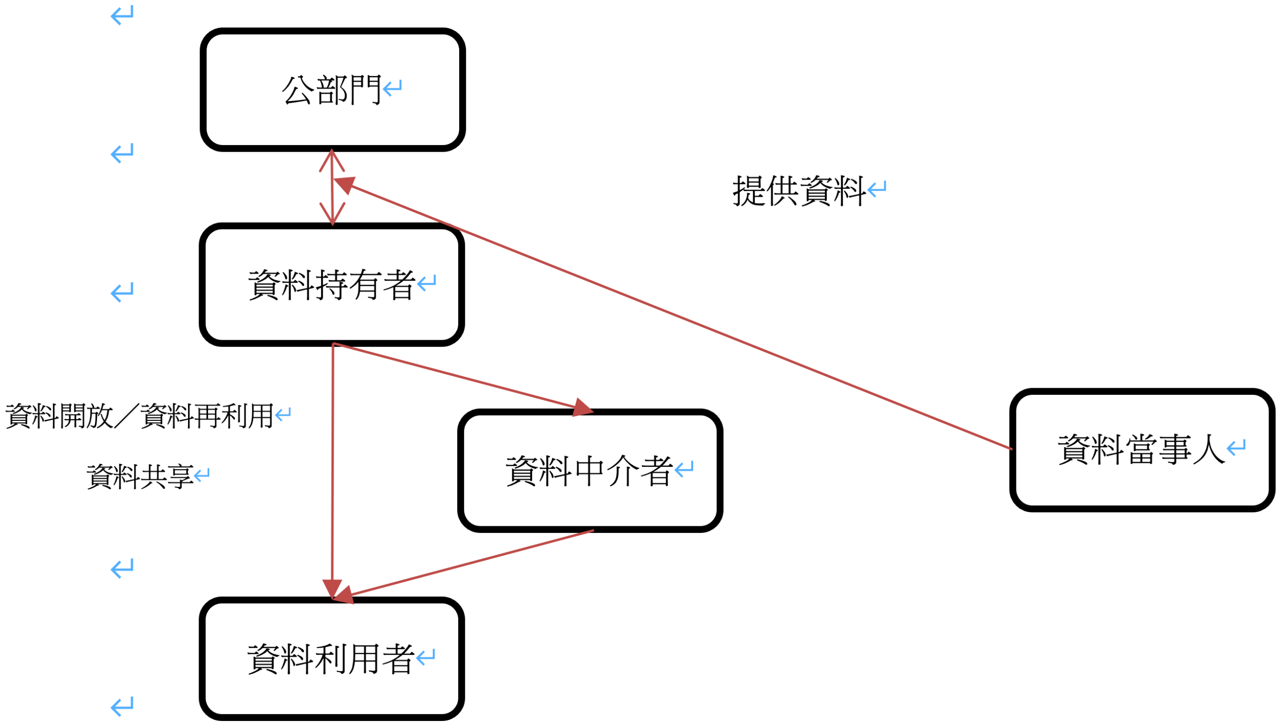
- 資料再利用之明確法規範
  - 台灣沒有
  - 歐盟說不夠
    - 在實務上對於包含有資料控制人或第三人之其他權利難以就該等資料再利用
    - 但是，如果在具有**明確的**公共利益且經利益權衡後確有必要，或當事人同意之情狀發生時，前揭包含有其他非個資當事人權利之資料非必不得再為利用。

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



公部門

提供資料

資料持有者

資料開放／資料再利用

資料共享

資料中介者

資料當事人

資料利用者

圖一：公部門持有資料再利用情境下的資料流關係

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
    - DGA第2(16)條之定義，資料利他主義是指資料當事人或資料持有者自願共享資料而不尋求報酬，以實現依據適用的（會員國）國家法律定義的公共利益目標，例如科學研究目的、政策制定或改善公共服務等。
    - DGA第25(2)條指出該等組織允有歐盟統一格式之資料利他同意表作為個人同意個資蒐集之制式文件，而該文件應使用模組化方法(modular approach)而能夠針對特定領域及不同利用目的進行客製化(customisation)。

資料利他

- 資料利他之組織規範
  - 資料利他
    - DGA前言第45點：
      - 使用資料主體在知情同意的基礎上自願提供的資料，或者在涉及非個人資料的情況下，由資料持有人提供，將很有可能實現普遍利益之目標。此類目標將包括醫療保健、應對氣候變化、改善移動性、促進官方統計資料的開發、製作和傳播、改善公共服務的提供或公共政策制定等。
      - 對科學研究的支持也應被視為普遍關注的目標。該等規範在促進在資料利他主義目的基礎上，應提供足夠規模的資料池，以實現包括在整個歐盟範圍內之資料分析和機器學習。
      - 為了實現這一目標，會員國應該能夠制定組織或技術安排，或兩者兼而有之的規範，促進資料利他主義。

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/錯誤 理解之焦慮
- 數位發展部願景之一：資料治理（DCMS ???）
- 個資專責主管（監管）機關...

謝謝聆聽

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