

Expert Report for the UK Covid-19 Public Inquiry

Module 2: Political and administrative decision making in relation to the Covid-19 pandemic

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Author statement

I confirm that this is my own work and that the facts stated in the report are within my own knowledge. I understand my duty to provide independent evidence and have complied with that duty. I confirm that I have made clear which facts and matters referred to in this report are within my own knowledge and which are not. Those that are within my own knowledge I confirm to be true. The opinions I have expressed represent my true and complete professional opinions on the matters to which they refer.

Gavin Freeguard
26th September 2023

About the author:

I started freelancing in January 2021 (my company is Gavin Freeguard Ltd, company number 13214981). I am currently:

- **Associate at the Institute for Government**, the UK's leading thinktank working to make government more effective, where I run the monthly Data Bites event series (which highlights interesting data projects across government), organise and chair other events related to data and digital government (e.g. private roundtables, party conference events, an 'in conversation' event with then-chair of the UK Statistics Authority, Sir David Norgrove), and sometimes support the Institute's Academy work (particularly co-facilitating workshops helping academics understand how to work with policymakers). I recently led a research project on lessons from government data sharing during the pandemic.
- **Policy associate at Connected by Data**, a campaign to ensure communities have a powerful say in decisions about data, where I am involved in work seeking to influence the Data Protection and Digital Information (No. 2) Bill and future data policy thinking, and helping to convene and coordinate civil society in their responses to the Bill (and in developing future thinking).
- **Special adviser at the Open Data Institute**, a non-profit with a mission to build an open, trustworthy data ecosystem and create a world where data works for everyone, where I have led projects on government's approach to 'data literacy' and mapping the key organisations responsible for 'data' in government, contributed to the ODI's response to the government's data protection consultation, supported other consultation responses and policy work (e.g. around the G7), hosted a 'data gameshow' as part of the flagship ODI Summit, and hosted a special edition of the ODI podcast. I served as interim head of policy between in late 2022 and early 2023 and continue to support the ODI's ongoing policy work (including on the regulation of artificial intelligence and the Data Protection and Digital Information Bill).
- **A member of the Public Digital network**, a digital transformation consultancy. I am not currently engaged in any active projects but have supported a project (with the Lisbon Council) on the eGovernment Benchmark assessing digital government across Europe, contributed to other work on using data at NHSX and data services in cities, and wrote about data visualisation during the pandemic for their Signals publication.

I have also completed work for:

- **Ada Lovelace Institute**, an initiative of the Nuffield Foundation whose mission is to ensure that data and AI work for people and society, where I supported a research and policy project and series of events on Covid-19 vaccine passports, and supported the Institute's response to the government's data protection consultation by helping organise a series of events
- **Royal Statistical Society**, the professional body for statisticians and data analysts, where I helped convene one of their public Covid-19 evidence sessions to help inform this public inquiry
- **mySociety**, not for profit group pioneering the use of online technologies to empower citizens towards greater civic participation, where I published a report recommending how they should establish a new research commissioning process, and supported their TICTeC Labs programme (which convenes global civic tech organisations to understand common challenges and commissions work to solve some of the problems)

- **Understanding Patient Data**, an organisation hosted by NHS Confederation (and previously the Wellcome Trust) to make the way patient data is used more visible, understandable and trustworthy, where I wrote a forthcoming long read on how the Covid-19 R number came to prominence and has been used in government decision-making
- **Full Fact**, the UK's independent fact-checking organisation, where I supported the publication of their latest annual report (with recommendations on how to improve the Online Safety Bill) through drafting chapters and organising and chairing a private roundtable
- **Defend Digital Me**, a call to action to protect children's rights to privacy and family life that works towards safe, fair and transparent data in education, where I conducted a review of the organisation's strategy
- **Think Digital Partners**, where I co-chaired a conference (and will shortly co-chair another)
- **Other clients** including The Forum, Imperial College London (a policy engagement strategy around data and AI); Global Government Forum (data analysis and visualisation); Smart Thinking (a webinar on data visualisation for think tanks); Apolitical (a session for civil servants on data analysis and visualisation); Lie Detectors (data analysis and visualisation); Epimorphics (facilitating an event on data catalogues); Nous (discussing UK digital government); Transparency International UK (reviewing their report on access and lobbying in UK housing policy); New Local (on how they can use data in their work); a possible new think tank (on their strategy); and The Alan Turing Institute (hosting a 'data gameshow' as part of their AIUK conference).

More details and links can be found in my 2021 year note (Freeguard, 2022) and forthcoming 2022 year note (Freeguard, 2023).

I am also a member of the UK Open Government Network steering group and HM Treasury's User and Preparers Advisory Group (for government financial reporting); a trustee of the Orwell Foundation; a former member of research commissioning panels for Administrative Data Research UK (ADR UK) and the Engineering and Physical Sciences Research Council (EPSRC); and a former member of the Office for Statistics Regulation public good of statistics research advisory group.

As for my previous experience:

- **Institute for Government** I joined the Institute as a researcher in August 2013 and, through several promotions, was programme director for data, transparency and digital government when I left in December 2020. I led the Institute's Whitehall Monitor project – which visualises and analyses data about government – and developed the Institute's organisation-wide capability and skills in using data. Our work has been used extensively by government, media and civil society and has helped secure improvements in how government publishes and uses data. I led and was involved in several research projects beyond Whitehall Monitor, on digital government, government procurement, international civil service effectiveness, the need for better data to improve outcomes for children and young people, and preparing politicians for government. I organised, chaired, hosted and facilitated many external and internal events; built and maintained relationships with senior stakeholders in government, politics, the media and civil society; wrote for news outlets and appeared on TV and radio; and presented to a range of senior audiences.

- **Rt Hon Harriet Harman KC MP** I was political adviser to Ms Harman, then shadow secretary of state for culture, media and sport and deputy leader of the Labour Party, between March 2012 and August 2013. I supported her, the Leader of the Opposition, and the wider party on culture, media and sport policy, particularly the Leveson Inquiry (and subsequent Leveson Report) on press regulation. I worked on cross-party talks and legislation, preparing evidence, developing policy and strategy, drafting and scrutinising legislative documents, and providing political advice. I liaised and managed relationships with key stakeholders, chaired and presented at meetings of leading politicians, coordinated work for parliamentary occasions; and otherwise scrutinised and responded to the work of the Government.
- **Media Standards Trust** I worked at the Media Standards Trust, a media policy think-and-do tank, between November 2007 and March 2012. My main role was as the first full-time administrator (and later deputy director) of the Orwell Prize, working with the directors of the MST and of the Prize to develop a lasting organisation for Britain's most prestigious prize for political writing (now the Orwell Foundation). I was also closely involved in influential work on press regulation and the future of news.

Reports, articles or papers I have published about the response of the UK Government to the Covid-19 pandemic are listed in the annex to this report.

Data Sharing Framework and Regulation

3. Please explain the typical barriers and challenges to data-sharing in the public sector including technical barriers, legal barriers and cultural and organisational barriers and a brief history of UK Government initiatives to address and overcome these. In answering this question you are asked only to provide a brief overview of these matters to provide context for the rest of your report.

You may wish to include brief details about the following Government initiatives:

a. Modernising Government White Paper (1999 to 2005);

b. The Cabinet Office Privacy and Data Sharing Report (2002);

c. Transformational Government: Enabled by Technology (2005 to 2010);

d. Data Sharing Review (2008); and

e. Government ICT Strategy (2010 onwards).

1. Many of the typical, longstanding barriers to data-sharing in the public sector – examined below – also hindered attempts to share data during the pandemic. For example, the government’s own technical report notes that ‘data acquisition at speed was extremely challenging’ (Whitty et al., 2022, p. 148) because of ‘a lack of understanding about exactly what data sat where across multiple organisations; a lack of routine relationships across some organisations; a lack of formal agreements and data governance processes in place at the outset of the pandemic; a need for an appropriate platform and sufficient data engineering capacity to onboard data swiftly’. The Office for Statistics Regulation, in its review of health and social care statistics during the pandemic, highlights ‘fragmented data owned by multiple bodies, legal barriers, inconsistent formats, legacy software, and non-digital data’ which resulted in challenges and ‘an over-reliance on burdensome manual processes’ (Office for Statistics Regulation, 2021, p. 11).
2. However, in many cases the urgency of the pandemic and the focus it brought on clear purposes for data sharing meant traditional barriers were overcome, at least temporarily. Some in government worry that the loss of the urgent purpose and political imperative to share data could return to a business as usual state (Freeguard & Shepley, 2023d). It is also possible that speed required rapid workarounds rather than ‘fixing the plumbing’ – improving the underlying data infrastructure – which have stored up their own challenges for the future. When discussing ‘barriers’ to data sharing, we should also acknowledge that some of these exist for very good reasons (such as protecting personal and securing sensitive data), and that ‘data’ may refer to very different datasets in very different contexts.
3. **Technical barriers** to data sharing include problems with data quality which make it difficult to use and share. This can involve everything from accuracy to a lack of consistency over time, but also often refers to the lack of existing standards (or failure to develop standards) which hinder interoperability between (and within) different systems and different datasets. There may be no technical infrastructure to share data securely and safely – and a lack of technical expertise to do so. Legacy IT is often highlighted as a challenge – old systems which are slow, specialist or otherwise difficult to use (and replace). ‘Technical debt’ refers to the future problems accumulated through choosing particular technical options – perhaps opting for an easier (or cheaper) but limited solution in order to deliver something at speed. (Some people have started to refer to the related concept of ‘data debt’ – developing datasets without thinking about standards and future needs.) In some cases, technical systems may be designed for specific tasks which cannot be easily adapted for other (future) purposes (data protection law, where the purpose for data collection has to be specified, can present related legal challenges). Another technical/legal crossover is data access to outsourced or procured systems that may end as contracts end.
4. **Legal barriers** are sometimes cited, such as legislation not giving necessary permissions or allowing certain uses of data. This may have been a problem in the past, but more recent pieces of legislation have either created legal gateways for sharing (for example, the Digital Economy Act 2017 or DEA) or

aimed to clarify the rules (Data Protection Act 2018, or DPA, and the General Data Protection Regulation, or GDPR). The National Data Strategy, for example, cites ‘a proliferation of powers to share data’ which ‘made it difficult for public authorities to understand what data can be shared’ and it taking ‘years’ to establish legislation to introduce new powers as having ‘historically prevented greater data sharing in the public sector’, but the DEA being one of the measures to ‘address these issues and simplify public sector data sharing’. The NDS notes research into the use of the public service delivery power within the DEA that identified barriers including resource constraints, a lack of awareness of the powers and a nervousness around data sharing, rather than legal challenges (Pope, 2019). There are still some barriers relating to legislation – there remain several routes for data sharing, the landscape can be confusing, and relatively new legislation means it is still a developing field where legal guidance and advice may be variable – but many morph into cultural and organisational ones, as they refer to the awareness of the powers already available rather than the availability of necessary powers.

5. **Cultural and organisational barriers** include:
 - a. A lack of guidance and understanding of and expertise in the law – or using legal barriers as an excuse not to share data
 - b. A fear of data sharing and the consequences if something goes wrong
 - c. A lack of incentives to share data – UK government departments are often considered silos that tend not (and are not incentivised) to work jointly, value from data sharing may not accrue to the department doing or enabling the work, problems fall between departmental boundaries, and there may be no coordinating body or appropriate leadership to help solve these problems. An increasingly common phrase is that the ‘missed use’ of data can be as damaging as ‘misuse’ of data – but there are few penalties for the former. All of this means it can be much easier for a department – or its leadership – to simply say no to data sharing
 - d. A lack of investment (in skills and systems) and resulting lack of capacity and capability
 - e. A lack of data skills and data literacy in senior leaders (although improvements are underway) (Tarrant et al., 2022). This also reflects a lack of senior leaders who have been promoted through data or digital routes and have lived, or at least understand, data-related issues. This in turn might be partly due to career paths and definition of roles within government data and digital professions being recent or still being developed
 - f. A lack of multidisciplinary working and silos between different government professions (too much distance between policy and delivery has long been considered a problem).
6. Some of these problems – such as challenges in working across departments, and fear and a lack of expertise which may partly stem from not having seen successful data sharing projects elsewhere in government – illustrate wider problems with government in general and broader knowledge and information management issues.
7. There are also some **political barriers**. In recent years, the UK state has been absorbed by other priorities, such as Brexit, which have delayed or distracted from technocratic reforms which have less obvious political salience and short term political benefit. There has been a great deal of turnover in the political leadership of the relevant departments – 12 Ministers for the Cabinet Office and 12 Secretaries of State at the Department for (Digital,) Culture, Media and Sport, to say nothing of responsible junior ministers, since 2010 – and leadership for the data agenda has moved about (from Cabinet Office/Government Digital Service, to DCMS, government data then heading back to Cabinet Office, and the Central Digital and Data Office being created within Cabinet Office from early 2021). A lack of public confidence in government use of data, and the political and reputational consequences of sharing data going wrong, could also be considered a political barrier.

8. Political barriers aside, the Centre for Data Ethics and Innovation (CDEI) report, *Addressing trust in public sector data use* (2020), opts for a similar typology of barriers:
 - a. **Technical.** Limited adoption of common data standards, inconsistent security requirements across the public sector – this prevents, delays or increases the costs of data sharing
 - b. **Legal ‘confusion’.** Despite existing gateways and legislation, departments can start from scratch and dedicate significant resources to legal advice, data sharing agreements can delay projects
 - c. **Cultural and organisational.** Incentives lacking – departments bear costs (and investment may be significant) or responsibilities while the benefits are felt elsewhere; potential reputational and legal risks.
9. The National Audit Office, in its 2019 report *Challenges in using data across government* (Davies, 2019), opts for a different classification:
 - a. **Strategy and leadership.** Government not treating – or investing in – data as a strategic asset; a lack of leadership across government (including a long-promised government chief data officer); funding pressures that can inhibit progress
 - b. **Data, systems and processes.** Inadequate data quality, a lack of standards leading to the same data being recorded inconsistently across government, legacy systems often only working for the policy they were built for
 - c. **Conditions.** GDPR heightening citizens’ interest in the use of their data which, on top of previous misuse, can discourage departments from making the most of their data or communicating the benefits of data sharing; silo working inhibiting progress; although legislation (such as the Digital Economy Act) is now in place to make effective and appropriate use of data easier.
10. It underlines the fact that ‘despite years of effort and many well-documented failures, government has lacked clear and sustained strategic leadership on data.’ A more recent NAO report on digital transformation in government suggests that while the Central Digital and Data Office is ‘laying good foundations’, more challenging milestones lie in the future and CDDO’s ‘small budget and headcount’ are already affecting its ability to drive change (Davies, 2023, p. 15).
11. The National Data Strategy (Department for Science, Innovation and Technology, 2020), commissioned in 2018 and first published in 2020, highlighted the following barriers to ‘data availability’ based on its call for evidence and further engagement:
 - a. a culture of risk aversion
 - b. issues with current licensing regulations
 - c. market barriers to greater re-use, including data hoarding and differential market power
 - d. inconsistent formatting of public sector data
 - e. issues pertaining to the discoverability of data
 - f. privacy and security concerns

- g. the benefits relating to increased data sharing not always being felt by the organisation incurring the cost of collection and maintenance
12. It identified five areas where action was particularly necessary: the quality, availability and access of data; standards and assurance; capability, leadership and culture; accountability and productivity (ensuring the former helps drive the latter); and ethics and public trust.
 13. Many government reports over the last three decades have highlighted some or several of these barriers. These reports, reviews and initiatives in recent decades include:
 - a. **government.direct: a prospectus for the electronic delivery of Government services** (Freeman, 1996). This 'prospectus for the electronic delivery of government services' considered the implications of electronic service delivery and computerised data. In particular, how the sharing of data could help with efficiency, avoid unnecessary duplication, provide better services (citizens could tell the government once if they had changed address and see all databases updated), reduce the passing of paper between departments for policy coordination, and provide better and more accessible statistics which could also help boost inward investment and allow the development of commercial products based on government information. The report wonders if legislation is necessary and appropriate to lift some inhibitions on sharing data between departments.
 - b. **Report on the Review of Patient-Identifiable Information** (Caldicott, 1997). Commissioned in light of growing concern about how patient information was used (largely due to information technology) and the need to balance confidentiality with the use of data in patient care. The report's recommendations included appointing 'guardians' – now Caldicott Guardians after the chair of the committee that authored the report – within each health organisation to be responsible for safeguarding the confidentiality of patient information, and six principles for the protection of patient confidentiality (the Caldicott Principles, of which there are now eight).
 - c. **Modernising government** (Cabinet Office, 1999). An 'information age government' (ibid, p. 44) should be at the head of using technological developments to meet the needs of citizens and businesses. This should include having a clear basis for inter-departmental data sharing while protecting privacy and human rights. It identifies the importance of data standards to support consistency; the problem of old systems making data access more difficult; the value of 'privacy-enhancing technologies' to minimise data access; and, in guarding against mistaken identity and misuse of data, that 'data protection is an objective of information age government, not an obstacle to it' (ibid, p. 51). All of this will be realised in part through stronger central coordination.
 - d. **e-government: A strategic framework for public services in the information age** (Cabinet Office, 2000). This again recognises the possibilities offered by information technology if concerns about security, privacy and confidentiality are addressed in order to establish and maintain public trust. In order to treat the information it manages as a 'corporate resource' (ibid, p. 21), the public sector will need to adopt various standards and consistent definitions around data and metadata. Annexes provide work programmes for delivering a 'privacy and data sharing policy' and a 'metadata policy' for 'Information Age Government' (ibid, p. 34).
 - e. **Privacy and data-sharing: The way forward for public services** (Cabinet Office, 2002). According to the foreword by Tony Blair, the report sets out 'the twin objectives of encouraging better use of personal data to deliver improved public services and safeguarding personal privacy'. This strategy requires 'significant change' in five areas – greater public trust (including through a Public Services Trust Charter setting out principles), new incentives and arrangements to improve reliability and accuracy of personal data in the public sector, using new technologies to support more secure and

joined up data use, modernising public sector management of information and privacy, and a better understanding of the operation of the legal framework (including a possible consultation on changing legislation).

- f. **Transformational government: enabled by technology** (Cabinet Office, 2005). This 'bold' strategy noted the technological opportunities – to which information sharing was crucial – for improving transactional services, helping frontline public servants, supporting effective joined-up policy outcomes, reforming government's corporate services and infrastructure and taking advantage of tech developed for the wider market. A 'ministerial focus' on finding the balance between protecting privacy and sharing data to provide better services included, as part of an implementation plan (Cabinet Office, 2006), a Ministerial Committee on Data Sharing to 'to develop the Government's strategy on data sharing across the public sector'.
- g. **Information sharing vision statement** (Department for Constitutional Affairs, 2006). This set out the government's vision 'for better, more customer-focused services supported by greater information sharing which will protect and support individuals and society as a whole' (ibid, p. 2). Existing benefits to information sharing included improving opportunities for the most disadvantaged, reducing crime and fraud, customer focused public services, reducing the burden on business, and more effective and targeted policy implementation. The future vision included stronger safeguards and transparency while encouraging greater information sharing within the existing law than was currently occurring, including through better support and guidance to 'front line practitioners in particular' about the Data Protection Act so they would understand the Act 'is not a barrier to appropriate information sharing'.
- h. **Service transformation: A better service for citizens and businesses, a better deal for the taxpayer** (Varney, 2006). Although identity management and data sharing are 'distinct concepts', there was 'frequent interaction' enough between them (and the former could underpin the latter) that this report recommended the government data sharing strategy should address impediments to sharing identity information. Making better collective use of government information assets 'is at the heart of the service transformation agenda', with key challenges including governance, sustained investment and 'balancing continuity of existing services with new demands to set priorities' (ibid p.42).
- i. **The Power of Information: An independent review by Ed Mayo and Tom Steinberg** (Mayo & Steinberg, 2007), and **government response** (Cabinet Office, 2007). This review, 'unusual' in being 'a story of opportunities rather than problems' (ibid, p. 3), looked at the use and development of 'citizen and state-generated' information. In recommending the release and reuse of public sector information, the review was a landmark in the development of the open data movement – sharing information outside government, with the public.
- j. **Data sharing review** (Thomas & Walport, 2008). This emphasised that while existing laws tended not to provide a barrier to personal data being shared, 'the complexity of the law, amplified by a plethora of guidance, leaves those who may wish to share data in a fog of confusion'. Its recommendations 'aimed at transforming the personal and organisational culture of those who collect, manage and share information', including leadership and training, transparency, clarifying the legal framework to support more authoritative guidance, enhancing the role of the Information Commissioner's Office and supporting secure environments for research and analysis.
- k. **Government ICT Strategy** (Cabinet Office, 2011). This underlined the importance of a common infrastructure underpinned by common standards and sharing and reusing IT services and solutions (which would also help open up supply chains). Transparency and user engagement would help set these standards around data and ensure such data was shared rather than

duplicated, and a Public Data Corporation would bring public data into one organisation to support data being opened up

- l. **Government Digital Strategy** (Cabinet Office, 2012a). This strategy – to be implemented by the new Government Digital Service – noted that some failures of online services were due to legacy IT systems and long-term contracts with expensive vendors preventing effective data sharing. It also discussed the benefits of opening up data across and beyond government through APIs and required departments to provide data on the performance of their transactional services
- m. **Open Data: unleashing the potential (White Paper)** (Cabinet Office, 2012b). According to Francis Maude's foreword, opening up data 'will empower citizens, foster innovation and reform public services'. Although the focus was very much on transparency, the White Paper was also 'determined' to improve data sharing ('where it is in the public interest and within legislative boundaries'), which might include clarification of the law, the creation of new legislative measures or challenging 'outdated and unhelpful perceptions' of data sharing. It identified 'administrative, legal and cultural' barriers and noted that strong measures in response to high-profile losses of data had led to risk aversion within public bodies to sharing data
- n. **Improving Access for Research and Policy** (Administrative Data Taskforce, 2012) and **government response** (Department for Business Innovation & Skills, 2013a). This made several recommendations to improve the research and policy use of administrative data (such as social security, tax and education records), including an Administrative Data Research Network, 'a collaboration between government departments and agencies, research funders and the research community that will reach across the UK to facilitate research based upon linked administrative data'. The government broadly supported the recommendations; ADR UK, launched in 2018, evolved from the initial ADRN
- o. **Shakespeare review of public sector information** (Department for Business, Innovation & Skills, 2013b) and **government response** (Cabinet Office and Department for Business, Innovation & Skills, 2013). This argued that public sector information was the foundation of the next phase of the digital revolution – processing and learning from data. The focus was again on widening access to public sector data as part of a National Data Strategy, but it also touched on the importance of privacy and confidentiality while increasing availability of data to external users (through sandboxes and safe havens).
- p. **Information: To Share Or Not To Share? The Information Governance Review** (Caldicott, 2013). This updated the Caldicott principles for using confidential information, which are to justify the purpose, don't use personal confidential data unless absolutely necessary, use the minimum necessary, that access should be on a strict need-to-know basis, everyone with such access should be aware of their responsibilities, they should comply with the law, and the duty to share information can be as important as the duty to protect patient confidentiality. An eighth principle – 'inform patients and service users about how their confidential information is used' – was added in December 2020.
- q. **Data Sharing between Public Bodies** (Law Commission, 2014). This found that there were some legal obstacles to data sharing and others from 'institutional attitudes and incentives or disincentives to share'. The proliferation of pieces of legislation and data sharing gateways made them too difficult to find and interpret. It recommended a 'full law reform project' to create a 'principled and clear structure for data sharing' to meet societal needs including 'efficient and effective government, the delivery of public services and the protection of privacy'
- r. **Allan Review of government digital records** (Allan, 2015) and **Better Information for Better Government** (Cabinet Office, 2017). This review and the government response grappled with the

growth in digital information and how best to manage such records. The Allan Review thought policies and guidance were 'sound' but that problems came in the implementation – the transition from paper to electronic records had undermined the rigour of information management

- s. **Government Transformation Strategy** (Government Digital Service et al., 2017). The chapter focusing on 'better use of data' pledged to remove barriers to effective data use (including using the Digital Economy Act), make better use of data through improving capability, managing and using data securely and appropriately (including appointing a chief data officer), creating registers (an ecosystem of authoritative lists of reference data to support services), opening up government data, improving data discovery tools, and transforming the way data was held and managed (including thinking of some government organisations as data custodians or registrars)
- t. **Data - unlocking the power of data in the UK economy and improving public confidence in its use** (Department for Digital, Culture, Media & Sport; Department for Science, Innovation & Technology, 2017), part of the **UK Digital Strategy** (Department for Science, Innovation and Technology et al., 2017). This pledged to support the data economy through better data infrastructure (the 'assets, technology, processes, and organisations' that allow data to be created and shared, like storage, software, networks and platforms) and improving data skills, building public trust through ethical frameworks for the use of data and reviewing data protection offences in the light of emerging issues and technologies, and using government data effectively through managing it better (including through registers) and opening it up
- u. **National Data Strategy** (Department for Science, Innovation and Technology; Department for Digital, Culture, Media & Sport, 2020). Two years (and four secretaries of state and two prime ministers) elapsed between the National Data Strategy being commissioned and it being published during the pandemic (and a 'high watermark' of data use in government). Data availability – including sharing within the public sector and between it and the private and third sectors – is one of the four pillars of the strategy; transforming government's use of data 'to drive efficiency and improve public services', which includes improving how data is shared across government and public services, is one its five missions.
- v. **Transforming for a digital future: Roadmap for digital and data, 2022 to 2025** (Central Digital and Data Office, 2022). This 'common cross-government vision' has 'better data to power decision-making' as one of its six missions, and includes actions on making all 'critical' data assets available across government (through APIs, Government Data Exchange – GDX and the Integrated Data Service – IDS), a data marketplace (to include a data catalogue, standards and governance models), a single data ownership model for 'critical' data assets, and ensuring 50% of high priority data quality issues will be resolved in a period defined by a cross-government framework. (The IDS is a cross government project led by ONS, that 'provides access to improved data, analytical and visualisation tools, in a secure multi-cloud infrastructure', allowing timely and relevant data to be shared securely across government, academia and the wider research community, in order to inform policy decisions and improve public services (Scott, 2023). The aims of GDX are, according to a contract award (Bidstats, 2022), that data sharing across government is based on easy, effective and secure common processes; data sets are discoverable and accessible; and departments are supported and working together to develop a unified data infrastructure that enables cross-government services.)
- w. **Data saves lives: reshaping health and social care with data** (Department of Health and Social Care, 2022a) and **Better, broader, safer: using health data for research and analysis** (Goldacre, 2022). The data strategy for health and social care has 'improving trust in the health and care system's use of data' as its first objective (and acknowledges mistakes made around General Practice Data for Planning and Research, see below). The Goldacre Review focused on how to

allow health data to be used for research and analysis while preserving patient privacy, making 185 detailed recommendations.

4. Please provide an overview of the legislation, guidance, policies and organisations involved in supporting and regulating data sharing in and across the UK Government immediately prior to the beginning of the pandemic in January 2020. In answering this question please provide in particular an explanation of the matters listed at (a) to (h) below and any other areas that you consider relevant, how they support the process for sharing data in and across government and any views about how they advance or inhibit data sharing:

- a. The Digital Economy Act 2017;*
- b. The Data Protection Act 2018;*
- c. Privacy and Electronic Communications Regulations (PECR) 2003;*
- d. The EU General Data Protection Regulation (EU-GDPR);*
- e. The UK General Data Protection Regulation (UK-GDPR);*
- f. The Data Protection Impact Assessment system;*
- g. Data Sharing Codes of Practice;*
- h. The role of the Government Digital Service;*
- i. The role of the Central Digital and Data Office; and*
- j. The Digital, Data and Technology Professional Capability Framework.*

14. Among other things (including provisions relating to broadband, online pornography and intellectual property), the **Digital Economy Act 2017** introduced powers allowing government departments to share data with one another for the purposes of digital government and public service delivery and ensuring privacy, consistency and clarity in how the public sector shares data. (The Act does not cover data sharing for the provision of health or adult social care.) This followed an engagement exercise with civil society. Data sharing agreements made under certain chapters of part 5 of the Act are published in a register (Cabinet Office & Central Digital and Data Office, 2021), and the government has published codes of practice alongside the Act (Cabinet Office et al., 2018). The ICO has just conducted a review (Information Commissioner's Office, 2023f) of data sharing under the Act, finding it 'provides a supportive background to help organisations share data in ways that benefit the public. The framework includes robust safeguards that ensure organisations share data responsibly and in alignment with data protection principles, while also safeguarding people's rights'. The Data Protection and Digital Information (No 2) Bill proposes some amendments to the Act.
15. The **Data Protection Act 2018** sets out the UK's data protection framework, replacing the 1998 Act and sitting alongside the General Data Protection Regulation. GDPR is one of three data protection regimes in the Act, the other two covering data processing by law enforcement and the intelligence services. The Act was amended on 1 January 2021 by regulations under the European Union (Withdrawal) Act 2018, to reflect the UK leaving the European Union. It is one of the pieces of legislation under which the ICO is empowered to take regulatory action (Department for Digital, Culture, Media & Sport, 2021). The Data Protection and Digital Information (No 2) Bill proposes some amendments to the Act.
16. The **Privacy and Electronic Communications Regulations (PECR)** sit alongside the Data Protection Act and GDPR and cover privacy rights in relation to electronic marketing, cookies or similar technology that tracks use of or access to services and websites, public communications services (like telecoms or internet service providers), and customer privacy in relation to traffic and location data, itemised billing, line identification services (caller ID), and directory listings. It is one of the pieces of legislation (ibid)) under which the ICO is empowered to take regulatory action. The Data Protection and Digital Information (No 2) Bill proposes some amendments, especially around cookies.
17. The **General Data Protection Regulation (EU GDPR)** is a regulation under EU law, adopted in 2016 and enforceable from 2018, that sets out principles, rights and obligations for the processing of personal data. Since the UK's departure from the European Union, it does not apply in the UK.
18. However, its provisions were incorporated into **UK GDPR** as the UK left the European Union. According to the ICO, 'In practice, there is little change to the core data protection principles, rights and

obligations' (Information Commissioner's Office, 2023e). It covers seven key principles (lawfulness, fairness and transparency; purpose limitation; data minimisation; accuracy; storage limitation; integrity and confidentiality; accountability) that should be at the heart of an approach to processing personal data (Information Commissioner's Office, 2023c); several lawful bases for processing data, including consent, public task and legitimate interests (Information Commissioner's Office, 2023b); and eight individual rights (to be informed; to access; to rectification; to erasure; to restrict processing; to data portability; to object; in relation to automated decision making and profiling) (Information Commissioner's Office, 2023a). At present, the EU has granted a data adequacy status to the UK – it considers the UK GDPR to provide an 'essentially equivalent' level of protection to personal data. This decision (which is expected to last until 2025) does not apply to some data transfers for the purposes of immigration control, where there is some divergence between the EU and UK versions. Since Brexit, businesses and campaigners have expressed concern that proposed changes to the UK GDPR could threaten adequacy. It is one of the pieces of legislation under which the ICO is empowered to take regulatory action (Department for Digital, Culture, Media & Sport, 2021). The Data Protection and Digital Information (No 2) Bill proposes amendments to UK GDPR.

19. **Data Protection Impact Assessments** are part of the accountability obligations in UK GDPR, which the ICO describes as 'a process designed to help you systematically analyse, identify and minimise the data protection risks of a project or plan' (Information Commissioner's Office, 2023g). There is no fixed format, but the ICO's template invites data controllers to explain their project's aims and why they identified a need for a DPIA; describe the nature (how will data be collected, used, stored and shared), scope (what sort of data, kept for how long, affecting how many people), context (nature of relationship with individuals whose data is being processed and their control over the use of their data) and purposes of the processing (intended effect and benefits); consider how best to consult relevant stakeholders; describe compliance and proportionality measures (lawful basis for processing, does it achieve desired purpose, how to ensure data quality); identifying and assessing risks and their potential impact on individuals; identifying measures to reduce or eliminate medium or high risks; and a sign off including who approved the measures and advice from the data protection officer. The ICO says DPIAs 'are not just a compliance exercise' but can help 'identify and fix problems at an early stage'. The Data Protection and Digital Information (No 2) Bill will relax requirements for record keeping, including for DPIAs (introducing assessments of high risk processing which have different requirements).
20. The ICO published its first statutory **Data Sharing Code of Practice** (Information Commissioner's Office, 2011) (following a recommendation from the 2008 Data Sharing Review, put into law by the Coroner's and Justice Act 2009). It is now prepared under the Data Protection Act, which requires the code to provide practical guidance relating to the sharing of personal data in accordance with data protection legislation, and any other guidance which is considered appropriate to good practice. Failure to comply with the Code might make it 'more difficult to demonstrate that your data sharing is fair, lawful and accountable' and complies with data protection legislation.
21. The **Government Digital Service** was created as part of the Cabinet Office in 2011, following a report (Fox, 2010) on the future of the Directgov website which recommended a central team in Cabinet Office with 'absolute control' of online government information and appointing a CEO for digital with 'absolute authority' over user experience in online services. GDS came to prominence through the new consolidated government website, GOV.UK, and a programme to transform transactional online services beginning with 25 'exemplars'. Its wider role in setting standards and providing platforms included programmes relating to data, including Registers. However, by 2019 a select committee report (Science and Technology Committee, 2019) expressed concern that GDS had 'lost its way somewhat', with its purpose less clear and having experienced several changes of ministerial and civil service leadership. (The government also rejected a recommendation, and a similar one from the Public Accounts Committee (Johnstone, 2020), to conduct an audit of data-sharing among government

departments.) In March 2018, a machinery of government change (UK Parliament, 2018) had moved responsibility for data policy and governance (including data ethics, data sharing and open data) from the Government Digital Service to the Department for Digital, Culture, Media and Sport, aiming to 'bring together in one place data policy for both government and the wider economy'. The change was reversed in July 2020 (UK Parliament, 2020), with DCMS maintaining responsibility for data policy for society and the economy. In early 2021, the government reconfigured its digital leadership, with the new Central Digital and Data Office (see below) taking on responsibility for leading the Digital, Data and Technology (DDaT) profession and cross-government strategy, standards and assurance, with GDS leading on 'building, supporting and iterating digital products, platforms and services that can be built once and used across government'.

22. The **Central Digital and Data Office** was created in early 2021 (see above). It describes its responsibilities as leading government's DDaT function, setting the strategic direction for DDaT in government, setting DDaT standards, assessing performance and assurance (including spend controls – approving certain spend on digital and technology) and leading capability development for the DDaT function. In addition to the CDDO, there is the Data Standards Authority (whose steering board is chaired by the CDDO) which 'identifies, improves and helps implement data standards that meet user needs' and 'leads the cross-government conversation around data standards'. It recommends several standards for working on data projects across government, under the Service Standard (around sharing metadata, observing data ethics principles and choosing the right data tools and infrastructure), Technology Code of Practice (including how to integrate GDPR into projects, making better use and better managing data) and working with APIs (supporting more reuse of data across government projects). A recent National Audit Office report (Davies, 2023) notes CDDO was established to provide fresh impetus to digital transformation; that it is laying good foundations but more challenging milestones are in the future; and that a small budget and headcount are already affecting intended reforms. In examining CDDO's mission around better data to power decision-making, the NAO considers the risk to be that 'this is a complex area' and that 'momentum may not be sustained due to the intrinsic difficulty of the task'.
23. The **Digital, Data, and Technology (DDaT) Professional Capability Framework** 'describes the job roles in the Digital, Data and Technology (DDaT) Profession and provides details of the skills needed to work at each role level'. It identifies 'data' as one job family, along with IT operations, product and delivery, quality assurance testing, technical, and user-centred design: the jobs within 'data' are data analyst, data engineer, data ethicist, data scientist and performance analyst (the technical family includes 'data architect'). Some individual departments have used this as a basis for their own framework (Gregory, 2022). The development of such frameworks and other cross-cutting resources reflects not only the development of DDaT in government following the creation of GDS, but also the wider 'functional agenda' (Cabinet Office, 2022) which aims to strengthen and standardise various functions that are common to and aligned across many government organisation (for example, HR, commercial and project delivery as well as DDaT). (These differ from civil service professions which focus on developing people with particular 'skills, knowledge or expertise'.)

5. Please explain the role of the Office of the Information Commissioner ('ICO') to regulate the sharing of data in and across government, including the Data Sharing Code published by the ICO. In answering this question, please focus on (a) the position immediately prior to the beginning of the pandemic in January 2020 and (b) how the role of the ICO in regulating data sharing by the UK Government to assist the response to the pandemic changed, if at all, during the period January 2020 to February 2022.

24. The Information Commissioner's Office (ICO) has several roles in regulating the sharing of data in and across government. In its most recent annual report (Edwards, 2022), the ICO outlines six categories which contribute to its strategic goals: supporting the public to assert their rights, including handling helpline calls and complaints; enabling innovation and economic growth through data protection laws and earning public trust; raising global data protection standards through international influence; taking regulatory action where organisations are not meeting their legal requirements; supporting the public sector (including through encouraging organisations to put 'transparency and accountability at the heart of their decision-making'); and delivering the ICO service experience.
25. It can take regulatory action under several pieces of relevant legislation (ibid), including the Freedom of Information Act in addition to the legislation listed in answer to question 4, above. Its regulatory powers include issuing fines (for serious breaches of UK GDPR, this can be up to £17.5m or 4% of annual worldwide turnover, whichever is higher) and other penalties. In 2021/22, the ICO issued four fines under the Data Protection Act (totalling £633k) and 33 under PECR (£2.9m). Among its fines under GDPR were a potential fine of just over £17m (eventually £7.5m) (Information Commissioner's Office, 2022b) of Clearview AI scraping images and data from the internet and use of facial recognition, and a £500k fine to Cabinet Office for disclosing postal addresses of New Year Honours recipients (this was reduced to £50k (Information Commissioner's Office, 2022a), as part of the ICO's revised approach to working with public authorities (Information Commissioner's Office, 2022c) which focuses on warnings, reprimands and enforcement notices rather than fines). The ICO issued 24 reprimands 'requiring organisations to improve their data protection practices', including to the Scottish Government and NHS National Services Scotland about not providing clear information to users of their Covid app.
26. The ICO's revised approach to the public sector (part of a wider strategic plan) (Information Commissioner's Office, 2022d) underlines its other roles around data sharing in government, such as engagement, providing support, and sharing good practice and guidance (including the Data Sharing Code of Practice and on data sharing more broadly) (Information Commissioner's Office, 2023d). Engagement with the public sector is designed 'to encourage compliance with data protection law and prevent harms before they happen', and includes working with the Cabinet Office and the Department for Science, Innovation and Technology (previously the Department for Digital, Culture, Media and Sport), to create 'a cross-Whitehall senior leadership group' on data protection. The ICO also conducts its own research on issues of concern or topical interest (ranging from private providers of public services being subject to the same transparency rules as public sector organisations, to the use of WhatsApp and other messaging tools in government) and other reports and reviews – for example, the ICO recently completed a review of the data sharing powers in the Digital Economy Act (Information Commissioner's Office, 2023f), following a commitment made by Commissioner, Elizabeth Denham, to the bill committee as parliament considered the Digital Economy Act.
27. In March 2020, the ICO published a statement about 'data protection and coronavirus' which said it would be 'reasonable and pragmatic' in its approach (Information Commissioner's Office, 2020a). It stated that data protection law does not stop organisations from sending public health messages or from 'using the latest technology to facilitate safe and speedy consultations and diagnoses. Public bodies may require additional collection and sharing of personal data to protect against serious threats to public health'. The National Data Guardian was among those welcoming the position, fully

endorsing the statement that 'data protection concerns should not stand in the way of appropriate information sharing' (National Data Guardian, 2020).

28. In April 2020, the ICO published a short document (Information Commissioner's Office, 2020b) setting out its regulatory approach during the start of the Covid-19 pandemic, acknowledging that it must adjust its approach given the severe pressures facing the public sector and businesses. It noted the flexibility provided by existing data protection law to use data in combatting the pandemic and its effects. (It updated this in July 2021, as restrictions eased.) The ICO also published guidance, in general and on topical issues, such as developing contact tracing apps (later publishing a formal opinion on the approach taken by Apple and Google) (Information Commissioner's Office, 2020c), and worked with those developing particular schemes in government, including continued engagement with the team building the Clinically Extremely Vulnerable People Service and a consensual audit of NHS Test and Trace. The ICO published a short report (Information Commissioner's Office, 2021) reflecting on the pandemic experience in November 2021 (noting that, though it had its challenges, the principles-based approach of existing law provided sufficient flexibility, and the law worked best where organisations put people's privacy expectations 'front and centre').
29. Another major change to the ICO during the pandemic was that a new Commissioner, John Edwards, started his term in January 2022, succeeding Elizabeth Denham, and heralding some changes in approach.
30. The Data Protection and Digital Information (No 2) Bill proposes to reform the ICO, abolishing the office of Information Commissioner (a corporation sole, where all powers and responsibilities are vested in the Information Commissioner) and creating the Information Commission (a body corporate that would take over the ICO's current functions), a reflection of the growth of the office and the importance of the role. The new Commission is given a 'principal objective' in carrying out its functions under data protection legislation to 'to secure an appropriate level of protection for personal data, having regard to the interests of data subjects, controllers and others and matters of general public interest' and 'to promote public trust and confidence in the processing of personal data'. It is also given a series of duties it must have regard to – including promoting innovation and competition – and requirements (such as preparing a strategy). Some of these, in tandem with other powers granted to the Secretary of State, have prompted concern about the Commission's independence (and the ICO itself expressed concern about some proposals in the initial consultation). But the ICO has said the Bill will 'ensure [his] office can continue to operate as a trusted, fair and independent regulator' (Department for Science, Innovation and Technology, 2023).
31. The Department for Science, Innovation and Technology took on responsibility for sponsoring the ICO from DCMS following machinery of government changes in February 2023.

6. Please explain the role of UK Government departments in facilitating the sharing of data across Government to assist the Prime Minister, Cabinet, senior officials and advisers to use data, particularly healthcare data, to make decisions. We have termed such individuals as ‘core political and administrative decision-makers’. We are particularly interested to understand the role of the Cabinet Office and the lead government department in a national emergency to coordinate the gathering, collation and dissemination of data for core political and administrative decision makers. In answering this question please focus on (a) the position immediately prior to the beginning of the pandemic in January 2020 and (b) how these roles changed, if at all, during the period January 2020 to February 2022.

32. It is difficult to answer this question fully from outside government – the centre of government is not always transparent about how it reaches decisions based on data and evidence, and there are some protections in place (for example, the section 35 exemption under the Freedom of Information Act for the development and formulation of government policy). However, the data being shared from across government with core political and administrative decision makers is likely to have been a combination of specific ad hoc requests; information gathering from units with the Cabinet Office requiring data from other departments; and ongoing requests tailored to specific routines, products or set piece events. The latter, according to the government’s own technical report (Whitty et al., 2022), included a daily data brief for the Prime Minister and other senior ministers, and the automation of reports for gold, silver and bronze situational reporting (sitrep) meetings. Projects like the Covid-19 dashboard (GOV.UK, 2023), which provided information for the use of political and policy decision makers and the wider public, also had their own analytical pipelines drawing together data from several sources across government.
33. To a certain extent, each government department and other government organisations will have their own approach to collecting, producing, using and managing their data, and organising their departmental structures around it. The different cultures, responsibilities and professional composition of departments will have some bearing on their approach to sharing data and their capacity and capability in managing it. Most departments have a role approximating chief data officer, though there are variations in title, seniority and representation at departmental board level, and the Treasury (for example) only appointed its first chief data officer in 2022. There will be a head of profession for each of the data-oriented civil service professions (including analysis, the Government Economic Service, Government Operational Research Service and other research services or professions) within each department.
34. The cross-government functions – particularly analysis and digital, data and technology, when it comes to data – also have a role in trying to standardise approaches across government, as do cross-government data standards (including those supported by the Data Standards Authority) in pushing for greater consistency of data. CDDO leads the DDaT profession across government, although repeated promises to appoint a permanent chief data officer (since at least 2017, renewed upon CDDO’s creation in 2021) have not yet been honoured (two individuals have held the role on an interim basis during the pandemic). The Office for Statistics Regulation also has a role – particularly in ensuring official statistics comply with the code of practice for statistics (‘national statistics’ being those that fully comply), reporting concerns with statistics and providing resources to support good practice. (The letters between senior staff of the Office for Statistics Regulation and officials, and from the chair of the UK Statistics Authority to Ministers provide a useful insight into data challenges during the pandemic.)
35. Several different units in Cabinet Office beyond CDDO and GDS – some of them created during the pandemic – play a role in supplying core political and administrative decision makers with data, although there is little official information that is publicly available about several of them. These include:

- a. Analysis and Insight: now more than a decade old, it mainly focuses on data about the civil service and government effectiveness
 - b. No 10 Implementation/Delivery Unit: various versions of this have existed over the last few decades. This unit tends to focus on driving the prime minister's top priorities across Whitehall, which includes using data to track progress and hold departments to account. The Implementation Unit became the Prime Minister's Delivery Unit again during Boris Johnson's premiership
 - c. 10DS (No 10 Data Science team): this was created during the pandemic, with (according to one tender) 'a remit to radically improve the way key decisions are informed by data, analysis and evidence' through 'enabling 10 Downing Street to utilise the best evidence, and cutting-edge data science in policy and decision-making process, ensuring the Prime Minister and staff are intelligent customers of analysis, and embedding a culture of evidence-informed policy' and 'provoking positive change across Central Government, through providing challenge and feedback, and collaborating across Whitehall to drive long-term systems change and collectively solve policy challenges. (Prime Minister's Office and Cabinet Office, 2021)'
 - d. Evaluation Task Force: this is a joint unit between the Cabinet Office and HM Treasury that aims to provide robust evidence on the impact of government policies and inform spending decisions. Its website has it as part of the Cabinet Office Delivery Group alongside the Delivery Unit, 10DS, the Government Strategic Management Office, a Delivery Architecture team (in the process of being set up) and i.AI, the 'incubator for Automation and Innovation', a new team which aims 'to identify and deliver ways to drive efficiency and effectiveness through digital products and automation'.
36. Another key change during the pandemic was the creation of the Joint Biosecurity Centre in May 2020 (now part of the UK Health Security Agency). This appeared to be an attempt to get a grip of the sense of chaos, particularly around data, at the centre of government.
37. For many senior decision makers in government, the use of data during the pandemic appeared to be (as Oliver Dowden put it in his foreword to the National Data Strategy) a 'high watermark' for data in government, with politicians and senior civil servants appreciating the power of data like never before. (Others, not least in local government – see below – might have a different view.) It gave impetus to new initiatives to share and use data across government (such as the National Data Strategy and Integrated Data Service) and efforts to equip senior decision makers to use data; for example, the Data Masterclasses for senior leaders (Tarrant et al., 2022). Conversely, others working with data in government are concerned that interest might wane now that the early days of the pandemic, and the clear sense of purpose and mission it brought, are over.
38. One development that brought data closer to senior decision makers was the use of dashboards to present data (as well as the charts in the daily data briefs given to ministers and presented to the public at press conferences). The public Covid-19 dashboard (see below) was the most prominent and successful example, though there were others behind the scenes. Dashboards perhaps reached their zenith with the 'control room' developed at 70 Whitehall. As the Covid-19 dashboard showed, they can be beneficial in presenting data in a clear, engaging and interactive way that meets the needs of their users and helps them interrogate the data, and bring the right people together around the right information to make decisions. But they can also present as a silicon bullet when they can only present a partial version of the truth, can give false certainty and obscure the messiness and incompleteness of the data underneath (fixating on the dashboards rather than 'fixing the plumbing'), prompt decision makers to respond to noise rather than signal, and – while they can be built in a low tech, experimental way – can also rot as decision makers abandon them.

39. A recent report by the Institute for Government (Tetlow & Bartrum, 2023) on the role of the Treasury during the pandemic shares several findings about the use of data at the centre of government:
- a. The Treasury played an important role in synthesising evidence from across government, and it produced strong analysis on the economic impact of the pandemic and economic behaviour
 - b. But the transparency of economic evidence pales in comparison to the transparency of scientific evidence – little was published, hampering external analysis and effective synthesis and potentially undermining the government’s ability to communicate with the public about the merits of public health restrictions. It was also poor at sharing much of its analysis – including in-depth economic analysis and projections – with others in government
 - c. The Treasury ‘worked quickly to use new real-time data sources in innovative ways to understand which parts of the economy needed support’ and shared this data with Number 10, Cabinet Office and other departments. It started – and has continued – to strengthen its data science capability
 - d. Until late 2020, sharing of information and synthesis of analysis at the centre of government ‘were weak’, as the Cabinet Office lacked ‘effective structures’ for drawing information from across government: ‘Instead, departments – including the Treasury – shared analysis strategically to support their particular point of view, with the chancellor feeling he needed to ‘make the economic case’ as a counter to ‘the health case’ that the health minister was making’, leading to ‘sub-optimal decision making’.

7. Please comment on any international standards or working groups that advised on or set out guidelines for data sharing to assist evidence-based decision-making during public health emergencies. In answering this question it would be particularly helpful to understand the GloPID-R Data Sharing Working Group and other similar initiatives and the extent to which, if at all, they were integrated as part of the data sharing framework of the UK Government before or during the pandemic from January 2020 to February 2022.

40. The Global Research Collaboration for Infectious Disease Preparedness, or GloPID-R, first met in 2013 and was formalised in 2014 (GloPID-R, 2014). It aims ‘to bring together funding organisations investing in research related to new or re-emerging infectious diseases to increase preparedness and facilitate rapid research response to outbreaks with pandemic potential, in order to save lives and limit economic consequences worldwide’ – it ‘represents a network of research funding organisations’.
41. It has a data sharing working group, established in 2016, which has as its goal, ‘improving funder policies to facilitate open science’ and aims to develop data sharing systems to support ‘research response’ during public health emergencies and feed into the World Health Organisation’s R&D blueprint to ‘accelerate and coordinate preparedness and response’. Before the Covid-19 pandemic, it had published three reports: on the principles of data sharing during public health emergencies (timely, ethical, accessible, transparent, equitable, fair, quality) (GloPID-R, 2018a), on learning from past outbreaks (GloPID-R, 2019b) with case studies on Ebola, MERS, yellow fever, cholera and zika, and on a roadmap for data sharing during an emergency (GloPID-R, 2019a).
42. From outside government, it is not obvious to what extent GloPID-R and similar initiatives were integrated into the UK response. GloPID-R is not mentioned in any of the key reflections on the UK’s pandemic response (for example, the government’s technical report or select committee reports). Indeed, international initiatives as a whole are seldom mentioned. The *Lessons Learnt* report (Health and Social Care Committee; Science and Technology Committee, 2021) expresses concern that the ‘structures for offering scientific advice’ lacked ‘international representation’ in general (as well as transparency and ‘structured challenge’). In his book with Anjana Ahuja, *Spike*, Jeremy Farrar describes ‘the uncomfortable feeling’ he had in January 2020 that ‘some of the information needed by scientists around the world to detect and fight this new disease was not being disclosed as fast as it could be’. He also relates the story of an academic publication releasing sequencing data for Covid-19, despite authorities in China having told one of the scientists not to do so. Modellers describe ‘back-of-the-envelope’ calculations based on any international data they could get hold of in the early days of the pandemic.
43. However, published sources cite several useful international initiatives. The UK government technical report mentions both the Global Initiative on Sharing Avian Influenza Data (GISAID), a ‘key’ channel for accessible data, and clinical studies made available via the UK’s International Severe Acute Respiratory Infection Consortium (ISARIC) Clinical Characterisation Protocol. It also considers the ‘global sharing of genotype information’ to have been a ‘critical part’ of the response. Farrar refers to ProMED-mail, ‘an online repository collating short descriptions of outbreaks of animal and human disease in different countries’ and publishing ‘other news snippets’ relating to disease, run by a non-profit initiative, the International Society for Infectious Diseases. According to one of the Royal Statistical Society’s Covid evidence sessions (Royal Statistical Society, 2022), other relevant international initiatives include the International Best Practice Advisory Group, which provided ‘weekly input and challenge’ to analysis from the International Joint Comparator Unit (established by the Cabinet Office and then-Foreign and Commonwealth Office in April 2020).
44. International data could provide challenges. As the UK government’s technical report notes, ‘case data were generally accessible but cross-country comparisons were unreliable because of biases such as differences in testing capacity, access, uptake and technologies deployed impacting data.’

Changes to the Data Sharing During the Pandemic

8. Please explain any key changes or developments to the data sharing framework particularly for healthcare data, to assist with core political and administrative decision-making in and across the UK Government that were implemented during the period of the Covid-19 pandemic between January 2020 to February 2022? As far as possible, please give an overview of the key changes, the reason for them and whether they were temporary to assist with data sharing during the pandemic or were part of a longer term data-sharing strategy by the UK Government and whether they were effective in assisting decision-makers? You may wish to identify your own key changes and developments but please explain in particular the following:

- a. The suspension of 'service assessments' by the Government Digital Service;*
- b. The UK Government's National Data Strategy published in September 2020;*
- c. The use of the General Practice Data for Planning and Research ('GPDPR');*
- d. The use of the Health Service (Control of Patient Information) Regulations 2002 (COP1); and*
- e. The UK Government's 'Data - A New Direction' consultation published in September 2021.*

45. One of the defining successes of the Government Digital Service is often said to be the service standard and accompanying **service assessments**. The service standard – part of the service manual – has 14 principles to help teams 'create and run great public services', ranging from understanding users and their needs (1) and creating a secure service which protects their privacy (9), to defining what success looks like and publishing performance data (10) and using and contributing to open standards, common components and patterns (13). If a service is the responsibility of a central government department and either it is a condition of spend approval, or it is a transactional service that is new or being rebuilt, then it must go through a service assessment. Here, several assessors will spend (on average) four hours asking questions and being taken through the service by the service team. At the start of the pandemic, given the speed with which teams were having to build new services, service assessments were suspended and replaced with peer reviews 'to ensure we are not taking time from already time-pressured teams'. These were two-hour long remote meetings where teams briefly presented their service demo; the panel would check key areas, mainly security, resilience, accessibility, and the ability to iterate after launch; discuss any pressing concerns immediately (with an email following the same day); and receive a report the following day with a traffic light rating (green, amber, red) and recommendations in key areas (many of which could be implemented after launch). Services were still expected to go through a full service assessment in future. Peer reviews were a pragmatic solution, balancing the need for services to be assured while allowing them to get up and running quickly – made possible through the existing controls and processes already existing and providing a model, even when they were relaxed. It seems CDDO may still be running service assessments remotely, and some departments are running internal assessments slightly differently.
46. The **National Data Strategy** (Department for Science, Innovation and Technology; Department for Digital, Culture, Media & Sport, 2020) was published two years after being commissioned (and seven years after the Shakespeare Review suggested such a strategy). It is often described as a framework strategy – it specifies various actions and their departmental owners, including implementing the recommendations of existing reviews and commissioning new ones, recruiting a chief data officer and leaders with data and digital skills, training public sector analysts in data science, launching an online portal for businesses to access training, and much more besides. The Strategy has several things to say about 'data sharing', which it groups with other terms (discoverability, availability, access, portability, mobility) to define 'data availability' as meaning 'an environment which facilitates appropriate data access, mobility and re-use both across and between the private, third and public sectors in order to generate maximal economic and/or societal benefit for the UK'. It identifies 'encouraging better coordination' as a key step towards greater data availability; pledges to create a central team of

experts able to ensure a consistent interpretation of the legal regime around data sharing; highlights some case studies to underline the importance of data sharing, such as the Clinically Extremely Vulnerable People Service (see below) and the Connected Health Cities project which ‘anonymises and links data from different health and social care services, providing new insights into the way services are used’, while also highlighting the role of data availability in fuelling growth and innovation; and in general celebrates the importance of effective data sharing in fighting Covid-19. Several teams across government certainly continued to use the NDS as a guide to their work (Civil Service World, 2022), and several of the actions in the NDS are underway.

47. In May 2021, NHS Digital announced a new service to improve the collection of patient data from general practitioners: General Practice Data for Planning and Research (GPDPR). (It should not be confused with either the General Data Protection Regulation – GDPR – or the GPES (General Practice Extraction Service) Data for Pandemic Planning and Research dataset – GPPR.) NHS Digital said that the pandemic had led to ‘a significant increase in the need for GP data from NHS Digital to support clinicians, researchers, academics and commissioners. This data could be used to improve health services through clinical research and operational planning, and it would replace the General Practice Extraction Service (GPES), which ‘performed adequately’ but was based on legacy technology. Due to come into being on 1 September 2021, the scheme was instead paused in July 2021 after controversy (Freeguard & Shepley, 2023c), with campaign groups and journalists complaining about a lack of transparency and the possibility of the private sector being able to use the data, and a legal challenge calling for a pause to allow patients to opt out since ‘rushing this major change through with no transparency or debate violates patient trust’. The number of patients exercising their right to opt out from their data being used doubled to nearly 3.5million. In pausing the programme, the NHS acknowledged it had made mistakes. Indeed, *Data Saves Lives* (Department of Health and Social Care, 2022) – the national data strategy for health and social care – begins with a section on improving trust and says ‘we made a mistake and did not do enough to explain the improvements needed to the way we collect general practice data... Not only did we insufficiently explain, we also did not listen and engage well enough. This led to confusion and anxiety, and created a perception that we were willing to press ahead regardless.’ The strategy underlines why the NHS wanted to roll out GPDPR – to improve data quality, improve the understanding of the health and care system to ‘plan better and provide more targeted services’, and to do so in a more cost-effective way (the current system ‘using ad hoc collection processes’, criticised by the National Audit Office and Public Accounts Committee, ‘is more expensive and inefficient’). And while patients should always be able to opt out, the more that do so, ‘the greater the risk that the quality of the data is compromised’. The strategy – different from the original draft, published in 2021 – pledges to learn the lessons of GPDPR. GPDPR itself did not learn the lessons of previous attempts to join up patient data across the health system, notably care.data, halted in 2014 and scrapped in 2016 over controversy about a lack of information given to patients (this was one reason the Major Projects Authority rated the project ‘red’ – that is, successful delivery appears unachievable).
48. The first **Control of Patient Information (COPI) notice** was issued in March 2020 and renewed several times up until June 2022. Made under the Health Service Control of Patient Information Regulations 2002, the notice required NHS Digital to process confidential patient information ‘for the purposes of protecting public health, providing healthcare services to the public and monitoring and managing the outbreak’ of Covid-19. (The national data opt-outs, referenced under GPDPR above, did not apply here.) According to some of those involved in the response (Freeguard & Shepley, 2023e), while the COPI notice did not solve everything right away (some people were still reluctant to hand over data, with initial legal uncertainty an inhibiting factor even though legal bases already existed for much of what they wanted to do), it sent a clear signal across the system that data should be shared and was intended to ‘give health professionals the security and confidence to share data to support the response to the pandemic’, allowing services (like the NHS Covid-19 Data Store) to be deployed more rapidly, data sharing agreements to be made more quickly and other processes to be streamlined and

flexed (such as the information governance framework). Those processing the data were still expected to comply with existing legal requirements, including those under GDPR. COPI was 'a badge of honour' (ibid), 'a security blanket, if you like, that sharing was safe', which helped open up conversations across the health system. The COPI notice expired on 30 June 2022. Any data sharing agreements reliant upon it have had to be moved to non-COPI legal bases.

49. In September 2021, DCMS published the *Data: a new direction* consultation, described as a 'first step in delivering on Mission 2 of the National Data Strategy to secure a pro-growth and trusted data regime'. (DCMS worked with several stakeholders in civil society, academia and industry to convene roundtable discussions around the consultation, although several accused government of not consulting properly.) The five chapters of the consultation covered 'reducing barriers to responsible innovation', 'reducing burdens on businesses and delivering better outcomes for people', 'boosting trade and reducing barriers to data flows', 'delivering better public services', and 'reform of the Information Commissioner's Office'. Chapter four, specifically on the public sector, is relatively short, with questions relating to whether the Digital Economy Act 2017 should be extended to help improve outcomes for businesses as well as individual citizens; clarifying that private companies processing data on behalf of public bodies can rely on the same lawful grounds for processing the data as the public body; clarifying that public and private bodies can lawfully process health data for reasons of 'substantial public interest' in health or other emergencies; introducing compulsory transparency reporting on the use of algorithms in decision-making for public authorities, government departments and government contractors using public data; either introducing a legal definition of 'substantial public interest' or adding to the list of situations which are always deemed to be of 'substantial public interest', to support the use of sensitive personal data; clarifying rules on police collection and use of biometric data, and standardise wording in legislation to allow more cross-sector working between intelligence and law enforcement services; and considering whether any of the proposals in the chapter would particularly impact people with protected characteristics. Other parts of the consultation would also have impacts on the use of data in the public sector – for example, around automated decision making (in chapter one), relaxing rules on data protection impact assessments and data protection officers (chapter two) and changes to the ICO (chapter five). The government published its response in June 2022, with many (though not all) of the proposed changes being taken forward into the Data Protection and Digital Information Bill, published for the first time in July 2022, before being paused in September. A new version of the Bill (with few changes) was introduced to parliament in March 2023 (Department for Science, Innovation and Technology, 2023).

50. Other developments in data sharing during the pandemic included:

- a. The ICO statement in March 2020 which said it would take a reasonable and pragmatic approach and that data protection legislation should not stop data sharing (see question 5, above)
- b. Polling (National Data Guardian, 2020) found that although many of those surveyed understood and agreed with the need to share data during the pandemic, more than two-thirds thought data sharing rules should return to what they were before
- c. CDEI's public attitudes to data and AI tracker survey, first published in March 2022 (CDEI, 2022b)
- d. Continued development of the Integrated Data Service (led by the ONS – see question 3), Government Data Exchange (GDS – see question 3), One Login (GDS) and digital identity (DCMS/DSIT and CDDO).

51. Two further things to note are that:

- a. Although emergency measures like COPI were used, existing provisions largely worked well: the foreword to the National Data Strategy notes that sharing information 'quickly, efficiently and

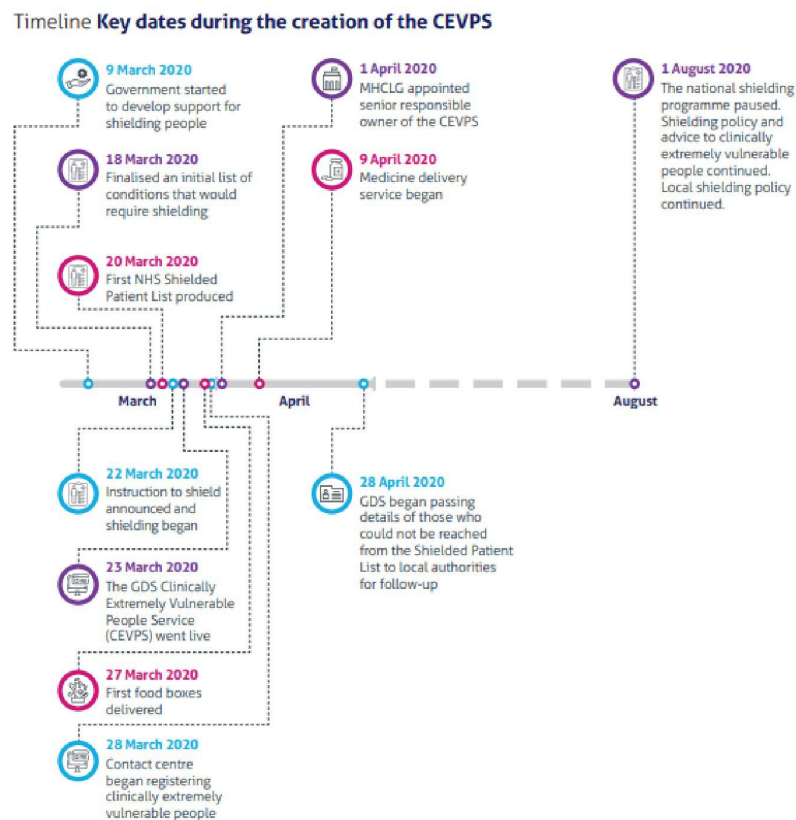
ethically' was a key part of the pandemic response, and the former Information Commissioner said the existing regime provided flexibility and enabled a pragmatic response (also highlighting the role of, for example, Data Protection Impact Assessments which 'benefitted both the business or organisation and individuals and consumers') (Information Commissioner's Office, 2021)

- b. The urgency, clear purpose and political imperatives behind the pandemic response supported rapid data sharing in a way not seen before.

9. Please provide an overview of the new digital services that were established by the UK Government to facilitate the response to the Covid-19 pandemic between January 2020 and February 2022. In answering this question please focus in particular on the new digital services that were established to assist with UK Government core political and administrative decision-making, in particular the gathering, collation and dissemination of healthcare data about the spread and transmission of the Covid-19 virus. You may wish to comment, for example, on the Covid-19 Dashboards and the Shielded Vulnerable Person Service developed for the Cabinet Office; the NHSX contact tracing app and the NHS Covid-19 Data Store.

52. The **Covid-19 dashboard** (GOV.UK, 2023) started life as a daily update on cases and death data in March 2020, produced by Public Health England. It evolved to cover five main pillars of data – testing, cases, healthcare, vaccinations and deaths – through nearly 200 metrics and is now updated weekly by the UK Health Security Agency. Users are greeted with some high-level numbers and charts for England, but can enter a local area (including in Scotland, Wales and Northern Ireland) for more detailed information including interactive maps. The site also provides extensive documentation and the ability to download the data or access it through an API. A multidisciplinary team behind the dashboard included interaction designers, user researchers and content designers who helped ensure that the dashboard could be as useful for and as receptive to the needs of the general public as possible. The dashboard uses more than 20 different data sources from government departments, different parts of the health system across the four nations, national statistical agencies and the House of Commons Library. While some of those datasets cannot be classed as National Statistics because of speed affecting the quality of data, the possible involvement of ministers and not being able to meet all requirements (such as pre-announcing release time and not restricting early access to the data), the dashboard has voluntarily applied the Code of Practice for Statistics. The dashboard has won several awards and plaudits for the quality of its presentation and analysis, documentation and openness (including those involved responding to questions on social media).
53. The Shielding Programme, Shielded Vulnerable Person Service, or **Clinically Extremely Vulnerable People Service** refers to a set of work designed to identify and protect the clinically vulnerable, by instructing them to remain at home to minimize their chances of catching Covid-19 while ensuring they would receive food, medicine and care. Development started on 9 March, and by 20 March NHS Digital had produced the first iteration of the Shielded Patient List (in around two days) using data from across the NHS, including Hospital Episode Statistics, general practice patient data, the Maternity Services Data Set and data on medicines prescribed in primary care, and later updated with manually input clinical judgments from NHS trusts, foundation trusts and GPs. This list was shared regularly with GDS, as the data controller for a separate CEVPS list. A full public-facing service went live on 23 March as the UK went into a national lockdown, including a website, a telephone helpline service and the infrastructure to collect, store and share data about who shielding individuals were and how they might be supported. The service was designed to provide support to the shielding population through the provision of food parcels, preferential access to supermarket home delivery slots, medicines and medicine deliveries, and access to care. The organisations involved included NHS Digital (data controller for the initial Shielded Patient List); the Department for Environment, Food and Rural Affairs (Defra), initially tasked to lead the service due to its existing links with food companies; the Government Digital Service, who built the service; the Ministry of Housing, Communities and Local Government (MHCLG, now the Department for Levelling Up, Housing and Communities); the Department of Health and Social Care; NHS England and NHS Improvement; GP surgeries; local government; wholesale food suppliers, supermarkets; and medicine and care providers. GDS developed a registration service and matching capability to identify individuals who wanted help, working with MHCLG to provide local authorities with relevant information about individuals who wanted support in their areas. Relevant data from the CEVPS List was also provided to supermarkets

and food, medicine and care providers so that support could be provided in various forms to people who registered with the service. The Department for Work and Pensions also set up an additional call centre whose tasks included phoning people and checking on their wellbeing. A NAO report (National Audit Office, 2021b) notes that the service was ‘pulled together at pace in the absence of detailed contingency plans’ and described the initial support as ‘impressive’ (food was provided to just over 500,000 people), though it took time to identify many people as clinically extremely vulnerable because of challenges extracting data from several different IT systems. Other data issues included: data being out of date (hospital data was immediately available but seven weeks out of date) – around 30,000 were contacted even though they had died before 20 March; data not always specifying the nature of a patient’s condition, meaning 126,000 people were unnecessarily advised to shield; personal details (such as phone numbers) were often missing, making it difficult to contact people; and local authorities say they received several different lists of vulnerable people (who could not be contacted centrally) that needed reconciling, and there was no feedback mechanism for them to return corrected data back to NHS Digital or GDS. The NAO also states that the need to share data swiftly and securely led to compromises in the design of data storage and sharing approaches (for example, people on the list struggling to update their own details).



Source: Adapted from *Protecting and supporting the clinically extremely vulnerable during lockdown*, National Audit Office, 2021.

From Institute for Government report (Freeguard & Shepley, 2022)

54. Matt Hancock, then health and social care secretary, first announced the government was planning to develop a **contact tracing app** at the daily coronavirus press conference on 12 April 2020. (This app

should not be confused with the existing NHS app, which would be used for Covid certification.) NHSX started to develop a 'centralised' contact tracing app (see below), which was trialled on the Isle of Wight in early May (by early July, over 50,000 – around 42% of the adult population – had downloaded it) (Department of Health and Social Care, 2020). By May and June, government rhetoric had started to shift – the trial apparently suggested people wanted to engage with human contact tracing first, and Baroness Harding, the test and trace 'tsar', described the app 'more as the cherry on the cake rather than the cake itself' (Health and Social Care Committee, 2020) – and the NHS Test and Trace Service launched, without the app, on 27 May. On 18 June, the government announced its work would shift away from the initial centralised NHSX app and towards working with the decentralised approach favoured by Google and Apple, having identified a number of 'technical challenges' including problems with the reliability of detecting contacts. On 11 September 2020, the government announced that, following trials in Newham as well as the Isle of Wight, the app would launch on 24 September. The Welsh Government also supported the use of the app. The Scottish Government trialled its own app which it launched on 10 September. Northern Ireland became the first part of the UK to roll out a contact tracing app on 30 July, a decentralised app in tandem with Ireland. A lot of the early discussion about contact tracing apps focused on the merits of 'decentralised' approaches, where all the processing of data and calculating of which other phones a user had been close to was done on individuals' phones, versus 'centralised' ones, where data collected on individuals' phones would be sent to a central, government-controlled server. Most countries, and Apple and Google (whose phone software would ultimately be running the apps), favoured a decentralised approach. The UK government initially favoured a centralised approach, arguing that a central server was necessary to give health authorities data on how the disease was spreading and would allow false alarms (including deliberate ones, or 'griefing') to be more easily reversed. The National Cyber Security Centre published a lengthy blog post (Levy, 2020) on how it would protect users' personal details. France also opted initially for a centralised app, citing public health reasons but also arguing (O, 2020) that embracing the Apple/Google model raised serious questions of accountability and power, with tech giants essentially dictating terms to democratic governments when the government should have a 'sovereign prerogative' to make choices about protecting the health of its people. The Blavatnik School of Government (Martin et al., 2023) wonders whether the app confused two different aims: the more limited one of alerting people, and a more ambitious one of providing data to decision makers.

55. Once the COPI notices were in place from March 2020, a team from NHS England and NHS Improvement and NHSX started to build the **NHS Covid-19 Data Store**, designed to provide the national organisations responsible for co-ordinating the pandemic response with secure, reliable and timely data from across the NHS and social care – a single or shared version of the truth to make informed decisions. The Data Store was a single repository of Covid datasets, built on Microsoft's Azure platform, and collected data from sources including NHS 111 online and call centre data, hospital admissions data, testing data and Covid-related deaths data. NHS England says this information was either anonymised, pseudonymised in line with guidance from the ICO or only made available in aggregate so individuals couldn't be identified. A single 'front door' interface was set up to manage requests from those wanting to access the data or add to it (they had to be able to demonstrate the request was for Covid purposes, justify the type and amount of data requested, demonstrate how it would be processed transparently and outline the legal basis for processing the data). This was managed by NHS Arden and GEM CSU on behalf of NHS England and NHS Improvement. Data processed via the Data Store was analysed using the **NHS National Data Platform**. Three dashboards were developed initially, to give real time data on the spread of the disease and the capacity of the health service to deal with it: a strategic decision makers dashboard for senior national and regional officials, an operational dashboard for local organisations, and a public dashboard with timely updates at national and local levels. These were followed by systems to anticipate where the virus might spread next and how that would affect services (early warning system); to manage the supply of critical equipment such as personal protective equipment (PPE), ventilators and oxygen supplies (Supply Chain 360); and to manage the Covid vaccination programme. The government and

NHS enlisted several private companies for support: Microsoft (support for technical teams on Azure), Palantir (its Foundry data platform software), Amazon Web Services (AWS, cloud infrastructure), Faculty AI (developing forecasts, such as the early warning system) and McKinsey and Deloitte (to help improve analytics capacity and capability). NHS England told the Institute for Government (Freeguard & Shepley, 2023e) that, at its peak, it estimated that around 400 people were working to support the Covid-19 Data and Analytics Cell in NHS England, in the joint team created between NHS England, NHSX, NHS Digital and other arm's length bodies, and with consultants and contractors. While the Data Store was a temporary project to enable the Covid response, supported by COPI notices, data sharing agreements have now been moved to a non-COPI basis in order to sustain the data. There was some controversy around the involvement of private companies in the Data Store. And although NHS England publishes details of the data included and its grounds for processing data, the National Data Guardian expressed disappointment at the time taken for a data dissemination register (around how data was used and shared) to be published (National Data Guardian for Health and Social Care, 2021).

56. The government rolled out several **other digital services** during the pandemic. By the end of May, GDS believed departments had delivered 69 new digital services with 46 more in the pipeline (Allum, 2020). A list provided to the Institute for Government (Freeguard et al., 2020) gives a sense of the variety of new services, some provided to the public (from claiming benefits, to asking a question at a coronavirus press conference) and some to business (like the Coronavirus Job Retention Scheme), and ranging from new websites (the coronavirus landing page, a social care recruitment platform), to new forms (registering as an 'extremely vulnerable person', reporting workplace safety concerns, businesses volunteering to help with ventilators), and to new notification services (text messages to people about Covid test results). The ability to build new services quickly was helped by clear political direction and urgency, using existing 'government as a platform' components (such as GOV.UK's design system, or the Notify system to send emails, text messages and letters), utilising existing infrastructure (such as DWP's application programming interfaces for sharing data) and building on existing experience and expertise (including internal capability through digital teams and building on strong relationships with external providers). As the contact tracing app shows, novel services proved more challenging. However, other services have received criticism, including the level of fraud on the Covid Bounceback Loan Scheme – even though, in the case of Universal Credit, fraud was made a secondary concern in order to ensure payments were made. For a fuller discussion of digital services during the first year of the pandemic, see IfG, Digital government during the coronavirus crisis (ibid).

10. Please describe the main organisations that held, and the main providers of, relevant healthcare data at the commencement of, and in the early stages of, the pandemic, for example, the public health agencies, the national health services (including hospital surveillance systems), syndromic surveillance data (such as the ZOE COVID symptom study, the NHS COVID-19 app, NHS Pathways data, the First Few Hundred (FF100) survey and online symptom reporting) and other prevalence studies (such as ONS CIS, REACT, SIREN and Vivaldi).

57. The main organisations holding and providing relevant healthcare data in the early stages of the pandemic included the various NHS bodies in the different nations of the UK and the government departments ultimately responsible for them (such as the Department of Health and Social Care in England); the public health bodies in the different nations of the UK (Public Health England and later the UK Health Security Agency in England, Public Health Scotland, Public Health Wales, and the Public Health Agency in Northern Ireland); and other government organisations (including the Office for National Statistics), consortia, academic bodies and private companies involved in studies and providing data and infrastructure for public sector activities.
58. Key organisations at the top of the English NHS as the pandemic began included NHS Digital (technically, the Health and Social Care Information Centre), the statutory safe haven for data, and the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care; and NHSX, a unit formed between DHSC and NHS England and Improvement to drive digital transformation in the health service whose units included the AI Lab and Centre for Improving Data Collaboration. NHS Digital and NHSX merged in February 2022 to form the NHS England Transformation Directorate. Further down the system, hospitals, GP practices and care homes were critical in collecting and providing data. Private companies also played a role (for example, see answer 9d, above).
59. England's public health infrastructure also changed during the pandemic, with the UK Health Security Agency being created during 2021, bringing together aspects of Public Health England, the Joint Biosecurity Centre (which had been set up in May 2020 to try to get a grip on data at the centre of government) and NHS Test and Trace.
60. Some of the key datasets inside the health and public health systems included:
 - a. **General Practice Extraction Service (GPES)** This collects data for range of purposes and allows the NHS to query GP systems to meet the needs to a particular data use case, such as providing the basis for payments to GPs or for health screening. It collects both 'effectively anonymised data' and patient-identifiable data (PID) that could identify an individual where permitted by law. It works in conjunction with GP clinical systems and the **Calculating Quality Reporting System (CQRS)** to help 'deliver an efficient and sustainable GP payment system', and data is used to help track the performance of GP practices against things including the Quality and Outcomes Framework (QOF), Vaccination and Immunisation (V&I) and the National Diabetes Audit. It also forms the basis of the **General Practice Extraction Service Data for Pandemic Planning and Research (GDPPR)**, a fortnightly extraction of data to help respond to the pandemic.
 - b. **Second Generation Surveillance System (SGSS)** This is a lab system designed to monitor notifiable diseases, such as TB, cholera, salmonella and MRSA (Covid-19 became a notifiable disease in early March 2020). It means labs around the country can test samples with a ready-made reporting pipeline back to Public Health England (previously) and UKHSA (now). It operates alongside the **Severe Acute Respiratory Infection (SARI) Watch** which replaced **CHES (the COVID-19 Hospitalisation in England Surveillance System)**, itself adapted from the UK Severe Influenza Surveillance System, in summer 2020. SGSS records demographics and diagnostic information

from lab tests for patients tested for Covid-19, while SARI collects demographic, risk factor, treatment and outcome information for hospital patients with a confirmed Covid-19 diagnosis. Together, the data is used for the purposes of 'direct care, service monitoring, planning and research in response to the spread of COVID-19'.

- c. **Secondary Uses Service (SUS)** This is a repository of primary healthcare information supporting clinical treatment, that can be utilised for secondary purposes such as planning, commissioning, policy development and national tariff reimbursement (a set of prices and rules used by NHS providers, replaced by the NHS Payment Scheme in 2023). One component of the dataset is the **Hospital Episode Statistics (HES)**, a database with details of admissions, A&E attendances and outpatient appointments covering NHS hospitals in England, with data originally collected as part of **Commissioning Data Sets (CDS)**.
 - d. **Demographics Batch Service (DBS)** This allows parts of the health system to submit a file of patient information to trace against the **Personal Demographics Service (PDS)**, the national database of NHS patient details including name, address, date of birth and NHS number.
 - e. **Covid Patient Notification System (CPNS)** Built by NHS England, this was 'the single reporting route' for hospital deaths where patients had tested positive for Covid-19, quickly adapted to include deaths with an absence of a positive test result but where Covid-19 was recorded as a direct or underlying cause of death.
 - f. **NHS Pathways** This is a tool for 'assessing, triaging and directing the public to urgent and emergency care services' which includes data from 999 and 111 calls and the use of the online 111 service.
 - g. **National COVID-19 Chest Imaging Database (NCCID)** Established by the NHS AI Lab as part of its AI in Imaging programme, this is a database of X-ray, MRI and CT images from hospital patients across the UK. It was created 'to support a better understanding of the COVID-19 virus and develop technology which will enable the best care for patients hospitalised with a severe infection', and was established by the NHS Transformation Directorate with the British Society of Thoracic Imaging, Royal Surrey NHS Foundation Trust and Faculty. Data is de-identified 'at the point of collection', is transferred in a way that builds on an existing clinical system (the Image Exchange Portal), and is made available to researchers, clinicians, technology companies and 'all those wanting to investigate the disease' who have applied.
 - h. **FF100** The First Few Hundred (FF100) protocol was put into effect as cases of Covid-19 began to appear in the UK, in line with previous pandemic responses and WHO guidelines. It aims to collect basic demographic data and enhanced clinical surveillance data on the first few hundred cases of a disease to help understand it. According to the government's technical report, it highlighted the increased clinical risk in people with underlying health conditions, and helps produce data early on. However, as explained in answer 13, the nature of Covid-19 meant that expected data was not forthcoming, and the technical report also notes FF100 data can be prone to bias (e.g. the first few hundred cases may share similar demographic characteristics, such as being returning travellers, and are therefore atypical).
61. Other healthcare data includes that from test and trace (including the Covid-19 app), and serological data, including testing samples of leftover blood from the NHS Blood and Transplant Service to understand the level of Covid in the population. The National Audit Office also notes the use of Primary Care Prescribed Medicines data and Maternity Services data (alongside Hospital Episode Statistics data and GP patient data) in the Clinically Extremely Vulnerable People Service.
62. The government also commissioned or used data from several other studies. These included:

- a. **National Core Studies** Government established the NCS programme in autumn 2020 to ‘ensure critical questions can be answered quickly’, building on areas identified by experts and key R&D funders. There were six core studies:
- i. Epidemiology and Surveillance, led by the national statistician, Sir Ian Diamond (ONS)
 - ii. Transmission and Environment (with a focus on workplace, transport and in public places), led by Andrew Curran (Health and Safety Executive)
 - iii. Clinical Trials Infrastructure, led by Patrick Chinnery, Medical Research Council, and Dr. Divya Chadha Manek, Vaccines Taskforce
 - iv. Immunity, led by Paul Moss, University of Birmingham
 - v. Longitudinal Health and Wellbeing, led by Nishi Chaturvedi, UCL, and Jonathan Sterne, Bristol Medical School
 - vi. Data and Connectivity (making UK-wide health and administrative data available), led by Andrew Morris, Health Data Research UK (HDR UK).
 - vii. The NCS produced data sharing principles and sought to bring together ‘core assets of the UK data infrastructure’ through the Health Data Research Innovation Gateway. HDR UK – the UK’s national institute for health data science, a charity funded by UKRI, DHSC and its devolved equivalents, and others – produced a few quarterly impact reports and other updates from January 2022 (the most recent being July 2022), and NCS is directed by an oversight committee (and an international panel).
- b. **SARS-CoV2 immunity and reinfection evaluation (SIREN)** SIREN was established early in the pandemic in partnership with healthcare workers, participants (45,000 across 135 sites) undergoing regular testing for up to two years. It aims to ‘evaluate the immune response to Covid-19, build understanding of the protection offered by vaccines and provide insight into Covid-19 reinfections’. SIREN was funded to the end of March 2023 and PCR and serology testing is paused as of 1 April while feasible future options are agreed (although SIREN has sought ethical approval for its records to be linked to immunisation and testing records until 2028).
- c. **Vivaldi** Launched in June 2020, Vivaldi focused on care homes in England and was a collaboration between UKHSA and University College London (UCL), with support from NHS England, University of Birmingham, the Doctors Laboratory and the Francis Crick Institute. The study collected demographic information, health information and treatment information to investigate the burden of Covid-19 infections in care homes, look for evidence of immunity, understand the effectiveness of vaccination and monitor how infections spreads in care homes. Between June 2020 and April 2022, the study tested 6,000 staff across 220 care homes. The study was due to end in March 2023.
- d. **ONS Coronavirus Infection Survey (ONS CIS)** Commissioned in March 2020, the Survey used answers to questions, nose and throat swabs, and (in some cases) blood samples to discover how many people had Covid-19, with some financial incentives for taking part. It was scaled up from an amalgamation of existing surveys, starting with around 10,000 households (England only) and increasing to around 360,000 individuals every month by October 2020 (across the UK, settling down to around 300,000 every month with changes to the digital survey), analysing more than 11 million swab tests and 3 million blood tests. The ONS also obtained data from NHS Digital to see how contracting coronavirus would affect participants’ use of the NHS in future (and participants

could also consent to their blood being used for further research). Data collection was paused in March 2023, with the UKHSA 'actively reviewing' Covid-19 surveillance and with it not yet clear what could come next.

- e. **Real-time Assessment of Community Transmission (REACT)** Commissioned by the Department of Health and Social Care (now managed by the UK Health Security Agency) and run by Imperial College London and Ipsos UK, REACT launched in April 2020. It used home testing kits to track the spread of Covid-19 (and later flu), supplemented by a short questionnaire. A follow-up study also tested cognitive function. Data collection for REACT ended in March 2022.
- f. **ZOE COVID** ZOE is a health science company whose first major project was around nutrition and involved participants in their study reporting back 'at-home' analysis. In March 2020, it launched the COVID Symptom Tracker app, which crowdsourced symptom data from people who had downloaded it – the company claims 4.7m contributors. The UK government technical report says the app shows both the strengths (speed of signals) and limitations (selection biases, poor comparability over time) of crowdsourced science. The study received government funding from July 2020 through to March 2022, managed by the UKHSA.
- g. **OASIS** Project OASIS was established by NHSX and jHub Defence Innovation (UK Strategic Command's innovation team, part of the Ministry of Defence) to collect data from third party symptom tracking apps (from commercial and academic organisations). jHub was commissioned 'to manage these third party apps, work with them to achieve assurance against the NHS standards and securely share their data with the NHS whilst protecting users privacy', since OASIS only works with apps assessed to the NHS Digital Health Technology Standard or against the Digital Assessment Questionnaire.
- h. **COG-UK** The Covid-19 Genomics UK consortium began life in March 2020: the UK government's chief scientific adviser, Sir Patrick Vallance, sought help from the 'pathogen genomics community' to explore sequencing Covid-19; phone calls and a meeting at the Wellcome Trust swiftly followed; and a proposal for COG-UK was circulated, resulting in a grant on 1 April 2020. It involved several hubs across the UK, including the public health agencies of the four nations, academic partners and other institutions, rapidly developing tools to sequence a large volume of genomic data. COG-UK closed on 31 March 2023 and is now being retired, with a hope that its data, expertise, seed-funded projects and lessons learnt will continue to inform genomic sequencing.

63. Another notable healthcare data initiative during the pandemic was:

- a. **OpenSAFELY** This was a system built by what is now the Bennett Institute for Applied Data Science at the University of Oxford, and limited to Covid-19 data as it was underpinned by COPI. OpenSAFELY allows approved analysts (who must document how they go above and beyond data protection law) to access patient data via a trusted research environment or software platform – the data remains in situ, with researchers taking analytical tools to the data, rather than bringing the data to the analysts. A group of 'digital critical friends' form, in essence, a public advisory group. (OpenSAFELY was approvingly cited in contrast to the initial attempts around GDPR, General Practice Data for Planning and Research, at an Institute for Government roundtable.)

64. The UK government's technical report (Whitty et al., 2022) provides a useful analysis of the different datasets available (from page 121), including a table comparing some of the key sources (from page 133). It distinguishes between:

- a. Testing data from clinical pathways (FF100, hospital admissions) and surveillance studies ('all had their pros and cons – triangulation was key'):

- i. Sentinel – repurposing influenza structures, such as CHES (the COVID-19 Hospitalisation in England Surveillance System) adapted from the UK Severe Influenza Surveillance System, and superseded by severe acute respiratory infection (SARI Watch) data (to include infections other than Covid-19)
 - ii. Syndromic – ZOE, the NHS Covid-19 app, NHS Pathways (111), online searching
 - iii. Prevalence studies – the ONS Coronavirus Infection Survey (ONS CIS), Real-time Assessment of Community Transmission (REACT), the SARS-CoV2 immunity and reinfection evaluation study (SIREN), Vivaldi
 - iv. Wastewater, measuring concentration of Covid-19 in different places
- b. Case data and genomic information, including whole genome sequencing (WGS) from surveillance study samples, case data and wastewater samples
- c. Healthcare data:
 - i. CHES (later SARI Watch) on hospitalisations, an aggregate and line list dataset providing data on general admissions and high dependency unit (HDU)/intensive care unit (ICU) admissions (sourced from sentinel sites and so not representative)
 - ii. Situational reports bringing together key management information from the four nations, including admissions, bed occupancy (later split between adults with and without Covid-19), available beds (general, acute, ICU), staff absences from Covid-19, CRITCON (assessments of ICU capacity)
 - iii. Secondary Users Service, a ‘comprehensive repository’ of healthcare data including Admitted Patient Care and Emergency Care Data, allowing linking of data (e.g. to infection, vaccination, variant, clinical characteristics and demographics, but not able to differentiate between underlying health conditions)
- d. Vaccination data (with both NHS England’s Primary Care Registration Management database and ONS mid-census estimates being used to estimate the size of the population – the denominator for calculations)
- e. Death data:
 - i. ONS weekly summaries
 - ii. Daily hospital deaths, later including deaths in other settings
 - iii. All-cause excess mortality (from the ONS and academia, later UKHSA and World Health Organisation too)
- f. Other non-health data, including:
 - i. Transport operators
 - ii. Educational establishments
 - iii. Search engines

- iv. Telecoms providers
- v. Behavioural and attitudinal data
- vi. Studies of contact patterns, such as CoMix and Covid-19 Scottish Contact Survey.

65. The Open Data Institute's crowdsourced map (Zimeta, 2021) of key data organisations in government gives some further information. The UKHSA provides further links on the Covid-19 surveillance (Covid-19 Infection Survey, Vivaldi, ONS Covid-19 Schools Infection Survey) and immunity (SIREN, Protective Immunity from T-Cells in Healthcare workers – PITCH) studies. medConfidential's briefing on data flows provides further detail, including links to documents and discussion of legal and technical points (supplemented by a review of the post-Covid landscape).

11. Please describe the main organisations that held, and the main providers of non-healthcare data, such as death data, behavioural data, and data from international travellers, transport operators, educational establishments, search engines etc.

66. In the 21st Century, every organisation in government is a data organisation (Zimeta, 2021) – collecting, holding, processing and using a variety of data for a variety of different purposes. This would have been true during the pandemic, with organisations across the public sector using non-healthcare data to inform their responses. Each of these datasets would require their own supporting infrastructures – or, as the government’s technical report puts it, ‘Each data set has its own story in terms of what had to be done to get what was needed to those who needed it.’
67. Looking just at the different academic groups modelling the R number gives a sense of the range of the key non-healthcare data sources (as well as underlining the importance of data not traditionally thought of as health data for health-related purposes). Some used school attendance data in England, a dataset the Department for Education published for the first time in April 2020, based on a form for schools to fill out daily.
68. Others used data about the behaviour of the population. Several modelling groups used Google Mobility data – ‘created with aggregated, anonymized sets of data’ from users who have a Google Account on their mobile device and ‘have turned on the Location History setting’. There were several behavioural studies used by modelling groups and others in government, including:
- a. **CoMix (Jarvis et al., 2020)** Run by the London School of Hygiene and Tropical Medicine, CoMix was a fortnightly social contacts survey that asked a representative sample the number of direct contacts they had the previous day, people with whom they had a face-to-face conversation and people with whom they had skin-to-skin contact. It also asked about adherence to physical distancing measures, such as lockdowns, and compared contact patterns to social contact during non-pandemic periods to estimate the change in the reproduction number as a consequence of physical distancing. It stopped collecting data in March 2022.
 - b. **COVID-19 Rapid Survey of Adherence to Interventions and Responses (CORSAIR) (James et al., 2022)** In 2012, NIHR funded a joint team from King’s College London, UCL and Public Health England (then, now UKHSA) to develop questions that could be used to assess people’s behaviours (and the influences and impact of official communications on them) during a future pandemic. NIHR activated the project at the start of the pandemic, as the Department of Health and Social Care and others started using surveys to understand public behaviour, with CORSAIR analysing the data from the surveys and making recommendations to DHSC, SAGE and others.
 - c. **Scottish Contact Survey** The SCS was a behavioural survey of a representative sample of the Scottish population, based on CoMix. It recorded adults’ direct face-to-face contacts on the previous day, ‘specifying certain characteristics for each contact including the age and sex of the contact, whether a meeting involved physical contact with another person, and where contact occurred’ in order to calculate an average number of contacts in a range of settings (home, work, school and other). Before April 2022, it was run as a rolling sample, with two panels of participants used in alternative weeks; from April 2022, the panels were merged and results were surveyed fortnightly; the survey closed in December 2022.
69. Data on deaths came from a range of sources. The Office for National Statistics data on death registrations is regarded as the gold standard – the Births and Deaths Registration Act (1836, updated by the 1953 Act) requires all deaths to be registered with the Local Registration Service and General Register Office in England and Wales – but had too long a lag (around 10 to 14 days) for some purposes during the pandemic. Public Health England merged their line lists (deaths from individual

hospitals) with the CPNS, SGSS data, and NHS Demographics Batch Service. If there was enough personally identifiable information (PII) in the data, PHE adapted a system they had previously used (to ensure anyone taking part in their research that had died would not receive any further correspondence), running their SGSS data through NHS systems to find people flagged as having died overnight and combining that with the actively reported hospital deaths gave them a 'backbone' of data on deaths.

70. The government's technical report (Whitty et al., 2022, p. 146) also highlights some of these specific non-healthcare datasets:
 - a. Mobility, from Google and telecom providers – by sector, of mobile phone network logs of cell connections. Not linked to health or patient data, used in aggregate form for population-level only
 - b. Social contact studies, such as CoMix and Scottish Contact Survey
 - c. Behavioural science, from YouGov (polling) and public health organisations (such as Public Health Wales' 'How are we doing in Wales' survey) – data on attitudes and other aspects influencing behaviour (e.g. in relation to non-pharmaceutical interventions, vaccination).
71. Several non-government organisations also used data to understand social, behavioural and other effects of the pandemic (for example, the Social Investment Business and Tortoise Media).

12. Please explain how data sharing of health data to show rates of infection, transmission, hospitalisation and death was organised between public and private data stores to assist UK Government core political and administrative decision-makers? We are particularly interested to understand how public and private data stores collaborated to gather data, for example the involvement of IQVIA and the National Biosample Centre with the ONS Infection Survey and the Royal Society's Rapid Assistance in Modelling the Pandemic (RAMP), the speed and ease with which such data was shared and the challenges faced with such collaborations.

72. The preceding two answers (and other material linked from the annex) hopefully address the broader questions of sharing of health data. On the more specific points:
- a. **IQVIA** IQVIA describes itself as 'a human data sciences company and leading global provider of advanced analytics, technology solutions, and clinical research services to the life sciences industry'. It was created in 2016 through a merger of IMS Health (known for its collection of healthcare data) and Quintiles (a biopharmaceutical and outsourcing service). As the ONS notes, IQVIA was the 'company collecting data on behalf of the ONS and the University of Oxford' for the Coronavirus Infection Survey, and participants would receive a letter from IQVIA inviting them to take part. IQVIA announced its involvement in April 2020 (and a May 2020 freedom of information response from the ONS gives some details of a contract award in 2021 following an open procurement procedure). IQVIA lists some of the key statistics from the Survey on its website (noting also Patrick Vallance's thanks for their work).
 - b. **The National Biosample Centre** The Centre was established in 2014 by a grant from the NIHR (National Institute for Health Research, since 2022 National Institute for Health and Care Research, established in 2006 to 'create a health research system in which the NHS supports outstanding individuals, working in world-class facilities, conducting leading-edge research focused on the needs of patients and the public'). It is run by UK Biocentre as a not-for-profit. The Centre, which builds on the experience of UK Biobank (a 'large-scale biomedical database and research resource' funded by government agencies, the Wellcome Trust, Medical Research Council and others), provides the 'logistical infrastructure allowing Investigators to deliver their study objectives'; it manages biological samples according to the needs of particular studies, and has no intellectual property rights over the samples it manages.
73. A participant information sheet produced by the ONS notes the involvement of the various bodies as follows:
- a. The Department of Health and Social Care funded the study
 - b. IQVIA was responsible for 'arranging appointments, managing participants taking their own nose and throat swabs, and taking the blood samples'
 - c. The National Biosample Centre was responsible for testing and storing the swabs
 - d. The University of Oxford was responsible for testing and storing the blood samples
 - e. The ONS, in collaboration with the University of Oxford, then analysed the data provided by the National Biosample Centre and the University
 - f. The Berkshire B Research Ethics Committee reviewed and gave a 'favourable opinion' to the study.
74. **The Royal Society's Rapid Assistance in Modelling the Pandemic (RAMP)** The RAMP initiative was established 'with the aim of mobilising the UK's wider scientific modelling community' to support pandemic modelling (particularly SPI-M, the Scientific Pandemic Influenza Group on Modelling, which

feeds into SAGE) in response to key policy questions. It received 1800 offers of support from individuals and teams – a number that left them ‘a bit overwhelmed’ – and paired volunteers with existing modelling teams to provide support, established a group to review new research, made use of a cross-sector group of actuaries to assess how different people were affected by Covid, and set up a number of new studies. The programme formally ended in July 2020, but several groups sought continuation funding to carry on their work.

Challenges Relating to the Use and Sharing of Data During the Pandemic

13. Please explain the challenges that were posed by the Covid-19 pandemic to the use of data, particularly healthcare data, to inform and assist UK Government core political and administrative decision-making during the pandemic? In answering this question we are particularly interested to understand:

- a. the limitations that there was on access for core political and administrative decision-makers to data on rates of Covid-19 infections, transmission, hospitalisation and death at the start of the pandemic until February 2022;**
- b. the challenges to the speed with which such data was made available to core political and administrative decision-makers;**
- c. reasons for any delays in the availability of such data to core political and administrative decision-makers including because of the need for data discovery, cleaning and processing and a lack of existing infrastructure;**
- d. how compliance with the data protection legislative framework impacted on the ability to share data and how this changed, if at all, between January 2020 and February 2022;**
- e. how the lack of such data, if correct, impacted on core political and administrative decision-making between January 2020 and February 2022; and**
- f. what measures were put in place to assist decision-making in the absence of such data?**

75. Data challenges in the early stages of the pandemic generally consisted of data that existed in some form but was difficult to share or collate owing to formats and processes; data that did not exist; and a lack of preparation, ranging from data flows not having been thought about or tested as part of pandemic preparedness exercises, to thinking through the use of personal data by government. Some of this can be traced back to longstanding challenges listed in previous questions, and a historical lack of data and digital literacy in senior government leaders (although the government itself notes – for example, in the National Data Strategy – that the pandemic experience brought the importance of data to the attention of senior leaders like never before).
76. Several key Downing Street figures have spoken about the lack of developed data pipelines and processes at the start of the pandemic. Data collection and collation was instead ad hoc, with officials emailing and being emailed Excel files, Word documents and text, and making phone calls, that had to be pulled together. For example, Cabinet Secretary Simon Case (2021) has said that the centre of government ‘started off with officials emailing Excel spreadsheets back and forth late at night, to be turned into PowerPoint slides for ministers the following morning’. The government’s technical report (Whitty et al., 2022) notes that at the start of the pandemic, ‘the main challenge’ in assembling the Cabinet Office dashboard that fed into the Prime Minister’s daily data brief was ‘inconsistent data formatting. Most government departments did not have the data engineering expertise required to set up APIs to facilitate data exchange and this meant that data sets often had to be assembled by hand which was time consuming and a potential source of error.’ (APIs and reproducible analytical pipelines were later developed, though some data ‘continued to be shared by other mechanisms (for example, email) throughout the pandemic’.)
77. Dominic Cummings, chief adviser to the Prime Minister at the start of the pandemic, told parliament this about data (2021):

In all sorts of ways it did not exist. The data system on Monday 16 March was the following. It was me wheeling in that whiteboard you have seen from the photo and Simon Stevens reading out, from scraps of paper, numbers from the ICUs. I would write them down on the left-hand side, and I would get my iPhone out and go x2, x2, x2. Then I would write another column and say, “So, if it’s doubling every five days,

these are the numbers we're going to be looking at." Everyone would look at the whiteboard and go, "Jesus—can that possibly be correct?" There was no functioning data system, and that was connected with there being no proper testing data. Because we did not have testing, all we could really do was look at people arriving in hospital. So the whole thing, therefore, is weeks and weeks out of date. Once you are looking at ICU numbers as your leading indicator, you know that you are in a world of trouble.

78. This was true elsewhere in the system. Marc Warner, chief executive of Faculty, an AI company working with the NHS, has said that the NHS system was 'completely dysfunctional in a fast-moving crisis. Thousands of spreadsheets a day were bombarding NHS headquarters and then being manually integrated in Microsoft Excel, through copying and pasting'. (Indeed, one of the selling points of companies like Faculty and Palantir is their ability to collate and ingest data from such disparate sources rapidly.) Public Health England was initially reliant on emails from hospitals about individual patients to start pulling together a 'line list' of deaths. Senior figures at Public Health Wales also report calling intensive care units to ask them what patients they had. Evidence given by Sir Patrick Vallance (2020) to parliament notes that NHS Trusts were required to input data manually into various systems, 'which was beyond NHS capacity at the time'. On top of information about cases being hard to obtain and collate, some sources have also suggested that basic operational information – such as the number of beds or ventilators available across the health system – was difficult to come by.
79. Vallance's evidence also suggests that data sharing protocols were agreed relatively late. A protocol for sharing data on returning UK travellers was agreed with modelling groups at DHSC and the wider SPI-M community on 17 February. The first line list data from Public Health England on suspected cases (including onset dates and testing data) was provided to modellers on 6 March. On 12 March, the decision was taken to stop testing except in hospitals, which cut off a critical data source: as one modeller put it, 'if you're only seeing the tip of the iceberg – hospitalisations, deaths – you don't know how broad that iceberg is'. Data on the social care system was largely unavailable to government – Vallance notes that SAGE #25 on 14 April deemed that data on cause of death in care homes was 'insufficient for modelling', and collecting data from such settings needed to be a priority. 'Fragmentation' of digital systems across the NHS is picked up by The Public Administration and Constitutional Affairs Committee (PACAC, 2021), quoting the National Audit Office – and Sir David Norgrove, then-chair of the UK Statistics Authority (while underlining that the statistical system had responded well on the whole), noted 'We currently have no coherent statistical picture of health in England or of the provision of health services and social care... The disparate bodies involved in the provision of health are in terms of statistical output too often inchoate, to the extent for example that both the NHS and Public Health England produce statistics on vaccinations that are published separately.'
80. Some of the reasons behind the lack of usable data have been covered in the section on the history of government data sharing, above. Several – including the challenges in different government organisations working with one another, or some actors (particularly social care and local government) not being represented in the right places – go beyond data sharing. But there are some factors more specific to the pandemic. Previous pandemic preparedness exercises touched on data, but not in much practical detail; where they made recommendations, they appear not to have been taken up. One of the best known drills, 2016 flu simulation Exercise Cygnus, recommended establishing a cross-government working group to clarify the 'process and timelines for providing and best presenting data on which responders will make strategic decisions' since participants 'were unclear about how epidemiological information would be produced and disseminated'. Cygnus was set in week 7 of an epidemic and focused on the 'treatment' and 'escalation' phases; it skipped the preceding 'detection' and 'assessment' parts, and 'recovery' at the end. (The US faced similar issues on the details of data flows: journalists at *The Atlantic* (Meyer and Madrigal, 2021) realised the US federal

government was relying on their data and noted pandemic plans ‘stressed the importance of data-driven decision making’ but ‘largely assumed that detailed and reliable data would simply ... exist. They were less concerned with how those data would actually be made.’)

81. Public Health England’s 2014 Pandemic Influenza Response Plan (Public Health England, 2014) notes that data collection protocols for the ‘First Few Hundred’ cases of a new disease (FF100) would only be possible ‘if a systematic approach’ had been developed ‘in advance’ (including contact tracing). While FF100 protocols were enacted as Covid-19 hit, the data that was available was different to the data upon which the plans had been predicated. The nature of Covid-19, disease and pandemic, was different to many of the planning assumptions. Other countries (including South Korea and Taiwan) had given more thought to data streams, legislation about data linkage and even suspending some privacy laws before the pandemic, while the UK debated some of these issues in the middle of the pandemic (though some of the data-related measures taken elsewhere may not have been as acceptable to the British public). Indeed, Sir Patrick Vallance told the joint select committee inquiry that a key lesson was that ‘data flows and data systems are incredibly important. You need the information in order to be able to make the decisions. Therefore, for any emergency situation those data systems need to be in place up front to be able to give the information to make the analysis and make the decisions’ (Vallance, 2021).
82. The availability of data improved as the pandemic went on, thanks to some of specific projects dealt with in answer to other questions, above, and the industry and ingenuity of public servants. (For example, Public Health England was able to spot that deaths had previously been underreported through combining the line lists it compiled from individual emails from hospitals with existing health and surveillance data, and applying a system it had used for research studies to ensure deceased participants no longer received messages.) Modelling played a vital role where data could not really be expected to exist – for example, metrics such as the reproduction number substituting for not knowing exactly how many people had the disease. Collecting and sharing data about a novel disease from disparate health and other organisations would be challenging at the best of times – but a lack of planning and existing problems with data systems did not help.
83. Further information answering this question can be found throughout the other answers in this document. Please see also the attached article on the origins of the R Number (as well as other material in the annex) for further detail.

14. Please consider the matters set out in question [13] and explain any variation between the approach taken by the UK Government and the challenges it faced with sharing healthcare data to assist and inform core political and administrative decision-makers and the position of the devolved administrations in Scotland, Wales and Northern Ireland. To the extent that there was any variation please explain what that was and the reasons for those differences.

84. There appears to be relatively little currently in the public domain that fully answers this question. This is itself interesting: devolution is often considered an opportunity to compare how different policies work. However, relevant points include the following:
- a. The devolved nations took different approaches to policy at times during the pandemic, which would have had implications for the flow and use of data. For example, as outlined above, Scotland and Northern Ireland took different approaches from England and Wales on the use of contact tracing apps.
 - b. There were also several similarities – for example, the government’s technical report notes that Wales (like Westminster) had an internal dashboard for decision-makers, and all four nations took complementary approaches to modelling (working in part through the SAGE and SPI-M-O structures).
 - c. Nonetheless, there were common frustrations – for example, the availability of data at the start of the pandemic, as shown in the answer to question 13, above, and in evidence to PACAC.
 - d. One example of a different approach was Wales having some frameworks for sharing data in place before the pandemic, specifically the Welsh Accord on the Sharing of Personal Information (WASPI). This outlined what data could be shared, in what format, with whom between organisations including local authorities, NHS Wales, public service providers and voluntary organisations. According to a participant at an IfG roundtable (Freeguard and Shepley, 2023a), this helped speed up data sharing agreements during the pandemic, avoiding the need to reach consensus during the crisis itself. (The Scottish Government is apparently considering a similar framework.)
 - e. PACAC’s report (2021) into data transparency and accountability – while explicitly not commenting on the ‘performance of devolved Government on devolved matters’ – notes some concerns from local government leaders about coordination on UK-wide issues, including ‘the dissonance between policy in different parts of the UK causing confusion to the public’ and officials. Some noted that while communications from the devolved nations had become clearer, ‘there is a bit of a gap with Westminster’. The joint report from the Health and Social Care, and Science and Technology select committees (2021) also makes the point that ‘the loss of consistency across the four nations led to confusion’.
 - f. Witnesses to the PACAC inquiry also suggest that in the devolved nations, local leaders were in regular contact with the devolved governments. For example, in Wales, local government leaders met regularly with Welsh Government ministers (‘regular and unprecedented access... that has allowed us to understand, shape and, to a degree, influence’ policy) and had ‘dialogue with and access to senior national advisers’ to help them understand the data. One Scottish witness said ‘we do not have the communication, as local government, with the Westminster Government that we would probably like’, in contrast to their ‘regular communication’ with the Scottish Government (there was a protocol set up for relations between local authorities and the Scottish Government).

15. Please explain any challenges in sharing healthcare data between the UK Government and local and regional administrations in England and what impact, if any, that had on the UK Government response to the Covid-19 pandemic between January 2020 and February 2022, particularly for example in making decisions on local lockdowns.

85. The UK government was slow to share data with local government during the pandemic, with the result that many parts of local government in England did not have the data they needed at a sufficiently granular to understand and combat the spread of Covid-19 in their areas – even when some of those areas were entering local lockdowns. Although data was eventually shared – in some cases, more quickly than might have happened in a non-emergency period – and there are some examples of innovation, local government was, according to one director of public health, ‘effectively blind’ at the start of the pandemic because data and epidemiological modelling tools were not being shared (Freeguard and Shepley, 2023a). As PACAC (2021) put it, ‘The Government knew the response would need to be localised and there were local systems in place to manage infectious diseases already... but, instead of allowing local systems to kick into gear, we got spreadsheets from Whitehall and officials refusing to share data’.
86. Several themes emerge consistently from reports on the challenges of data sharing between central and local government during the pandemic:
- Local authorities were ‘an afterthought’ in government planning. For example, the Greater London Authority told a select committee inquiry (Health and Social Care and Science and Technology Joint Committee, 2021) that there was a ‘strong sense’ local public services had ‘consistently been omitted from central Government’s initial thinking on designs for data sharing’. PACAC (2021) was told that an ‘inflexible’, ‘national by default’ response ‘had impeded their ability to work in their communities’. Even those involved in the Clinically Extremely Vulnerable People Service, one of the more successful data-enabled interventions, acknowledged they could have engaged local government more at the start (Freeguard & Shepley, 2022).
 - Data shares were ‘too slow to establish and to become functional’, according to the report by the Health and Social Care, and Science and Technology committees (2021); while this was a problem between public bodies of all types, ‘this was especially true in the data flows from national to local government’.
 - This was complicated by central government choosing to set up schemes, such as Test and Trace, outside existing systems, leading to technical challenges: according to the then President of the Association of Directors of Public Health, setting these systems up ‘in silos’ outside the emergency planning and public health systems meant ‘there was no way in which those [Covid-19] test results could easily flow into the public health system’. There were also data quality issues.
 - Local government felt that central institutions lacked a general understanding of the role of local government, and specifically why local government was asking for the data it was (often at a granular, patient-identifiable level): ‘there was definitely a sense of, “You do not really need that data at a local level”’. As a result, local government felt it was having to expend a lot of energy making different requests at different meetings (the central government castlist often changing). There is also scepticism from local government about the quality and timeliness of the data it was provided with by central government, as well as its granularity.
 - Different local government organisations have different levels of maturity, capability and capacity for working with data, partly driven by skills gaps and recruitment and retention issues (part of a longer list of existing barriers to data use and data sharing highlighted by CDEI (2021), also including budgetary constraints, poor data quality, a lack of legal clarity and insufficient demand

from frontline teams). This may partly explain a lack of trust from central government in sharing data with local government organisations, despite public health teams (in particular) having experience in dealing with sensitive data.

- f. Local government encountered challenges sharing data with local voluntary organisations, because of existing challenges in accessing and sharing data.
- g. There is a lack of incentives for data sharing between different levels of government which can contribute to this risk aversion. This includes local government not always seeing the benefit of data it contributes to central government – for example, the work that goes into supplying data for the Single Data List (a list of datasets local authorities are required to provide to central government – this was suspended early on in the pandemic though other data was requested) with little perceived benefit or data provided back in return.
- h. The number of organisations and overlapping jurisdictions means it can be difficult to find who holds and is responsible for particular datasets and there may be multiple sources, data can be held in different formats (even between e.g. district and county councils covering the same area) making it more difficult to use, and data may not be easily available for particular administrative geographies.

87. Data availability did improve as the pandemic went on – with more test and trace data, at a more granular (postcode, then patient-identifiable) level, with more useful metadata (such as UPRNs – an address identifier), and with later datasets (e.g. on vaccinations) learning some of the earlier lessons. There were also examples of innovation and central government support. These include the Ministry of Housing, Communities and Local Government (MHCLG, now DLUHC) having a Covid-19 Challenge Fund, organising ‘teach out’ sessions (for example, to support local authorities on data about the clinically extremely vulnerable) and, based on feedback from local authorities, improving data quality (e.g. adding UPRNs); the Joint Biosecurity Centre also ran open, national learning workshops; Local Data Spaces and other collaborations between local authorities and other organisations including universities (not an option available to all local authorities); the Local Government Association supporting local authorities, including using its LG Inform platform to fill in data gaps from existing public sources. The UK government has already said it will accept certain relevant recommendations – for example, its says it accepts recommendation 5 of the ‘lessons learnt’ report (Department of Health and Social Care, 2022) and Science and Technology select committees on establishing and testing ‘flows of data between bodies relevant to an emergency response’.
88. However, many of the problems above go beyond data sharing and speak to wider challenges. The last decade or so has seen a ‘hollowing out’ of local government which, according to the Blavatnik School of Government (Martin et al., 2023), was exacerbated by the lack of financial certainty for extra pandemic costs (along with a lack of trust from central government). This meant local government in England ‘did not have the infrastructure, capabilities, data or governance frameworks to execute a localised approach effectively’. Local authorities felt cut out of design processes in general – such as the design and practicalities of implementing test and trace. As part of its plans to implement the Levelling Up white paper, the government is currently establishing an Office for Local Government (Oflog) whose ‘primary purpose’ is ‘providing a transparent and authoritative source of information about the performance of local government’, although further public information is scarce (beyond that gleaned from job adverts) more than a year after its creation. Such an institution could provide an opportunity to reset the relationship around data between central and local government, but – if it is regarded as yet another central government imposition on local government – it may be a lost opportunity.

16. In addressing the following questions, we are concerned with data on race/ethnicity, and also data relating to the following 'other inequalities' characteristics: Sex/gender, disability, health inequalities, sexual orientation, age, socio-economic status, occupation, Gypsy and Traveller communities.

- a. Was there any unified national system of data capture that could apprehend rates of infectivity, rates of Long Covid or death rates based on race/ethnicity or other inequalities?**
- b. What barriers, if any, exist(ed) to capturing data on race/ethnicity and other inequalities in public health systems, and what measures (if any) were taken to overcome them?**
- c. Were there any efforts made to develop or improve data collection on race/ethnicity or other inequalities during the pandemic, in particular to (i) disparities in Covid-19 infections and outcomes among these groups; and (ii) any disproportionate impact of non-pharmaceutical interventions on these groups? If so, what were they?**
- d. Did a lack of comprehensive data on race/ethnicity and other inequalities impact the ability of decision-makers in the UK Government to respond to the pandemic effectively, particularly in terms of addressing health inequalities and responding effectively to COVID-19 outbreaks in communities of colour and among other inequality groups?**
- e. Can you comment on to what extent data on domestic abuse (for example data on reports of crimes involving domestic abuse, occupancy rates of refuges) was available to, and considered by, decision-makers when making key decisions about non-pharmaceutical interventions?**
- f. What lessons can be learned or recommendations made arising from any issues arising in relation to (a) - (e) above?**

- 89. The system for capturing data around race, ethnicity and other characteristics was no more unified than any other data systems. Although some health data does include further information around demographic characteristics and there were some initiatives to improve data collection on inequalities and disparities during the pandemic, the government has acknowledged that there are data quality issues and made several recommendations for improvement.
- 90. According to the government's technical report (Whitty et al., 2022), hospital admission data 'rapidly began to produce signals on potential disparities' as early as February 2020, with older adults, men and people with certain underlying health conditions found to be at risk. Intensive care data publication 'supported a rapidly growing understanding of ethnic disparities' – in the first wave, rates of hospitalisation among patients of black and Asian ethnic groups were high compared to those who were white. Forms for lab reporting included age and sex, with ethnicity added through linking to Hospital Episode Statistics data (the technical report says that the use of COPI notices helped enhance data sources with clinical and demographic information). There were specific reviews, including Public Health England's 'Disparities in the risk and outcomes of Covid-19' (June 2020) which was largely based on cases presenting at hospital (where testing was concentrated); this highlighted important disparities around infection risk and clinical severity by age, ethnic group, sex and occupation. Another PHE report, 'Understanding the Impact of COVID-19 on Black and Minority Ethnic (BAME) Communities' (2020), produced a series of recommendations on how to better understand and mitigate the impact of the pandemic on ethnic minority groups including one about improved data collection on ethnicity, occupation and faith in all routine clinical data and death certification. These reviews prompted further work by the Equality Hub and Race Disparity Unit (see below). Several of the early Covid-19 studies also allowed analysis for particular characteristics – for example, the ONS Covid Infection Survey around occupation, ethnicity and deprivation.
- 91. The technical report (Whitty et al., 2022) says that there was an expansion and update of what disparities data was collected and published through the pandemic – from hospital admissions by age and sex at the start to a longer list. Swab testing through NHS Test and Trace increasingly gave data at scale – including on age and ethnicity. The report notes that by the second wave, the weekly Covid-19

surveillance report incorporated more disparities data. By February 2021, the QCovid algorithm was being used to expand the shielded patients list, using data on ethnicity and local deprivation (as well as clinical information) to help assess a person's risk. From May 2021 onwards, PHE published CHIME (Covid-19 Health Disparities Monitoring for England) which included reporting on disparities, although it – like several other datasets – did not have access to underlying conditions, limiting the extent to which it could adjust for comorbidities. Access to other major datasets, such as OpenSAFELY, also allowed 'continuous surveillance' though there were apparently occasional sharing, linkage and timeliness issues. The technical report also underlines the importance of speaking to communities and local directors of public health, which 'helped highlight emerging issues in their communities' alongside the data, and the need for multiple methodologies (including qualitative ones, like interviews and focus groups) to gather information on drivers of disparities.

92. Looking at the R number highlights some of the possible effects of not having more granular data on particular characteristics. A letter to the British Medical Journal in May 2020 (Uzoigwe, 2020) made the point that 'The metric is clearly predominantly of value where there is equivalent and homogenous infectivity and gravity of infection throughout the population. However this is clearly not the case'; even in the early stages of the pandemic, it was clear that particular ethnic groups (specifically the black population) were being particularly affected and the R number would be higher in these communities. The letter writer observed that such groups 'effectively suffer 3-tier medico-political disenfranchisement – namely, limited access to socio-economic equality, being exposed to a pathogen with potential racial tropisms and, thirdly, being bound by policies founded on metrics relating to the low risk cohort'. Such divergence between different groups should call into question R's 'utility as a metric upon which important political decisions are made'. Some of those involved in modelling the R number also noted that they did not have the data available to them to dig into some of these questions – one noted that they would be told people with 'pre-existing conditions' had been hospitalised, but they did not have the data on which conditions these were, which could have helped with forecasting.
93. One challenge with data on particular characteristics is disentangling the main drivers of risk and understanding which are risk factors and which are confounding factors – for example, according to the technical report, crowded and multi-generational housing is a risk factor, linked to socio-economic status and more common in Bangladeshi, Pakistani and black African groups compared to white British; similarly, certain occupations, from frontline health and care workers to taxi drivers, also carried a heightened risk and South Asian populations have a higher probability of working in these professions. The technical report notes that the socially excluded – including those experiencing homelessness, the Gypsy, Roma and Traveller communities, vulnerable migrants, and sex workers are also likely to experience stigmatisation and discrimination alongside overlapping risk factors (though does not give much further detail).
94. Nonetheless, the technical report (Whitty et al., 2022) shows that:
 - a. 'As a single group, ethnic minorities experienced higher all-cause death rates and death rates from COVID-19 compared to those of white British ethnicity, with relative differences varying throughout the pandemic and across different ethnic groups'. The Race Disparity Unit's December 2021 final report points to Oxford University research finding 61% of people with South Asian ancestry carried the gene responsible for doubling the risk of respiratory failure from Covid-19
 - b. 'In the working-age population, COVID-19 death rates were consistently and markedly higher for men than women throughout the pandemic'
 - c. 'Another group at particularly high risk for severe disease and premature mortality were those with a disability. In the first wave, 6 out of 10 deaths in England were among people who reported having a disability' – this was particularly marked for those with a learning disability, but there are

limitations to the learning disability register and not all analyses adjusted for underlying conditions

- d. 'Co-morbidities such as diabetes, severe asthma and obesity were identified as risk factors for poor outcomes, and were more prevalent in more deprived and in some ethnic minority groups'
- e. 'Linked primary care records of over 17 million adults with over 10,000 deaths between February and December 2020 found that while comorbidity did explain some of the different death rates by ethnicity, people from black and South Asian ethnic groups were both more likely to test positive and more likely to die from COVID-19 during the first wave compared with people from white ethnic groups after adjustment for deprivation, age, sex and comorbidity'. In the second wave, disparities for south Asian ethnic groups remained but the disparity was less stark for black ethnic groups.

- 95. Challenges with this data include the fact that it is so sensitive, and – as the technical report puts it – 'was being asked of communities with relatively low trust in government organisations and understandable concerns about privacy and the use of their data', hence a lot of focus in that report on building trust with communities. There are also issues around data quality and collection being patchy and inconsistent. These are important points and echo beyond Covid: for example, while there is understandable sensitivity around this data, public services need to better understand how different groups are accessing services in order to ensure they are inclusive; protected characteristics can be complex and multidimensional, and some can be particularly difficult to measure (such as socio-economic background); and data gaps still exist (see Open Data Institute, 2021). The importance of data bias may become more pronounced with automated decision-making – the government's *Data: a new direction* consultation specifically asked about the processing of personal data in order to monitor, detect and correct bias in AI systems.
- 96. There is also a long running challenge about data on ethnic minorities not sufficiently distinguishing between different groups – the government's Equality Hub has written about the problems with using 'BAME' and similar terms [in general](#) (Race Disparity Unit, 2022). Its final report on Covid-19 disparities says a key lesson from the pandemic should be not treating ethnic minorities as a homogenous group, a 'one size fits all' approach not being effective – and there being issues with sample sizes for small groups.
- 97. Various government documents have drawn their own lessons and made recommendations. The technical report notes that the pandemic reflected and exacerbated existing inequalities. It notes a 'renewed effort' to address pervasive inequalities, highlighting equity audits of waiting lists and the Duty to Reduce Inequalities placed on the emerging integrated care boards (England). It also says that research on where disparities are, what causes them and how best to reduce them needs to begin at the outset of a pandemic; that a wide range of research methods will be needed; and that continual dialogue with communities is vital for understanding risks and co-designing responses to them – this includes ensuring such groups are involved in thinking about routine data sets, surveillance systems and research and planning exercises for future pandemics.
- 98. The technical report also notes that ethnicity recording on NHS systems is of poor quality. This is picked up elsewhere, including a SAGE subgroup which recommended improving data quality as an area for further research in March 2021, but particularly in reports by the Race Disparity Unit. Their final report on addressing Covid-19 health inequalities, published in December, says key lessons include improving the quality of health ethnicity data so patterns and trends can be spotted more quickly, and continuing to monitor the impacts of Covid-19 by ethnic group. It has an entire chapter on data quality, with recommendations including that:

- a. DHSC should continue to consider NHS England's UISPC (Unified Information Standard for Protected Characteristics) recommendations to improve the quality of ethnicity data coding
 - b. ONS to collaborate with others to consider how linking Census and health data could be improved (annual population updates do not include breakdowns by ethnic group, hence the use of the Census)
 - c. NHS Digital should include the proportion of records coded as 'not known', or 'other' or 'any other ethnic group' in the NHS Data Quality Maturity Index
 - d. Collecting ethnicity be mandatory as part of the death certification process
 - e. Datasets across government be harmonised and use the Government Statistical Service ethnicity standard, and the use of long Covid codes be increased and improved
 - f. Data quality issues around ethnicity be properly reported
 - g. Representation of ethnic minority groups in surveys be increased
 - h. The ONS database for health and care statistics (in England) be developed.
99. The report also notes discussion between the Race Disparity Unit and the Office for Statistics Regulation on several of these issues, with improving ethnicity coding in health datasets and reviewing data access for research being high priority.
100. Other reports echo many of these findings. For example, PHE's June 2020 review found the completeness of ethnicity recording in many health datasets was low (hence the need to link with Hospital Episode Statistics), and people from certain ethnic groups were less likely to have an NHS number), while the 'unequal impact?' report from the Women and Equalities committee (2020) similarly notes the problems caused by ethnicity not being recorded in death registration (contrasting with Scotland, where this has been the case since 2012), and those from a lack of transparency about what ethnicity data the government is collecting and from the disaggregation of health data.

Lessons-Learned and Recommendations

17. Please set out your views on successes, failings and lessons learned with regard to the sharing of healthcare data with core political and administrative decision-makers during the pandemic. In answering this question, please include details of any reviews undertaken into UK Government and the devolved administrations data sharing, including work by the Institute for Government, the National Preparedness Commission, the Royal Society and others. Please also identify areas for recommendations that the Inquiry may wish to consider in this field.

101. Too often, the right data was not available to the right decision makers, at the right level of detail, at the right time to make a difference. PACAC correctly notes the ‘remarkable effort’ involved in pulling together so much data ‘from a standing start’, with much of it being made available to the public. But a lot of the hard work and innovation shown by public servants and others during the pandemic could have been done in advance if greater thought had been given to the detail of data flows (including public acceptance of data-related measures) during a health emergency, and if previous proposals to reform data in government had been treated with greater strategic importance. There is also a risk that the lessons from the pandemic are not learnt and that the lack of urgency provided by the pandemic response enables a return to ‘business as usual’ and government not making the most of using and sharing data.
102. Several reports (including those from PACAC (2021); the ‘lessons learned’ report from the Commons Health and Social Care, and Science and Technology Committees (2021); the Institute for Government (Freeguard & Shepley, 2023d); the Royal Society, in 2020 (The DELVE Initiative, 2020) and 2023 (Hopkins Van Mil, 2023); the Blavatnik School of Government (Martin et al., 2023); the National Preparedness Commission (2022); the National Audit Office (2021a); the Office for Statistics Regulation (2021); and the government’s own technical report (Whitty et al., 2022) have come to conclusions and made recommendations around data sharing. Consistent themes include:
103. **Understanding, preparing, testing and improving data availability, systems and flows in advance.** Data sharing protocols and agreements were too slow to come into operation; some key data was unavailable at the start of the pandemic; and where data did exist, it was often in a form that was difficult to share and collate.
104. As the government’s own technical report puts it:

Good data are essential for an effective pandemic response – otherwise decision-makers, service providers and researchers are flying blind. Lack of even basic data was particularly acute in the early stages of the pandemic but difficulties with accessing, sharing and linking data persisted for much longer, although the situation improved significantly thanks to the efforts of those involved.
105. As per question 3, a lot of the challenges to data sharing in government (some of which were overcome, at least temporarily, during the pandemic response) are longstanding and have been identified by reports going back years, if not decades. Revisiting those recommendations and understanding why those initiatives worked or didn’t work would be a useful starting point for government – as would ensuring government has the right budget and headcount to support improvement, an issue recently highlighted by the National Audit Office (Davies, 2023).
106. Various pandemic-related reports cover similar ground:
 - a. The ‘lessons learned’ select committee report adds the suggestion of a mechanism to resolve any disputes immediately to establishing and testing emergency data flows.

- b. PACAC raises the need to ensure ministerial and departmental accountability for 'ensuring key decisions are underpinned by data, and for the data that underpins the decisions'. It also recommended that the Department of Health and Social Care, with support from the UK Statistics Authority and peer review from the Cabinet Office, should undertake an 'urgent review' of health data systems, and consider the role of DHSC in bringing together health data from different bodies.
 - c. The Royal Society calls for a review of technological capabilities and data standards across government, including devolved administrations, public bodies and local organisations such as local resilience forums. It suggests that regular government-conducted stress tests, related to risks in the National Risk Register, should also be applied to private sector organisations (and should include the implications of power outages for data access). And it recommends that, as part of reviewing data legislation, the government should provide greater clarity about the data that can be collected for emergency responses (whether predictable events like flooding, or rarer 'black swan' events), and the ICO should develop relevant guidance.
 - d. The IfG recommends that the Central Digital and Data Office should create a data sharing playbook for public servants looking to build new services founded on data sharing, which could contain templates for standard documents, links to relevant legislation and codes of practice (like those from the Information Commissioner's Office), guidance on public engagement, case studies covering who to engage and when whilst setting up a new service, and link to existing resources.
 - e. Similarly, the National Preparedness Commission calls for a standard playbook of protocols that could be informed by developing a greater understanding of data sharing during 'peacetime'. Like the IfG – which notes how useful Data Protection Impact Assessments were to those working on data sharing projects, and calls on government not to abolish them in forthcoming legislation – the NPC calls for DPIAs to be used to shape and evidence data sharing. The NPC also suggests that previous lessons are fed into a nationwide table top planning exercise that includes data sharing (supported by relevant training and identification of process improvements).
 - f. The government's own technical report says that in a future health emergency, data from across the health service, other health agencies in government and academia will need to be 'shared rapidly' and linked, which will require 'data governance processes and interoperable data platforms'. Four areas are worthy of particular thought: which data will be required (with consideration of who is responsible for the data and how it will be accessed), which datasets will need to be linked and how, who will analyse the datasets, and which datasets will need to be created. While some data lags are unavoidable (for example, between infection and hospitalisation), others reflect operational processes and could be avoided.
 - g. The OSR underlines the importance of multidisciplinary working and calls for statisticians and analysts to be involved in the creation of any new operational systems – some of the new infrastructure established rapidly during the pandemic 'did not always consider future data and publishing needs', giving NHS Test and Trace as an example.
 - h. The National Audit Office calls for the Department of Health and Social Care to set out in advance the core data requirements it is likely to need in a future pandemic or other civil emergency – and how it can access such data in a timely manner.
107. Any reviews or preparation exercises should test diseases with different characteristics and consider what would be necessary at different stages of a pandemic response. They should also map what systems data are held in and what, in practical terms, flows should look like.

Improving how central government works with other actors, particularly local government (but also researchers).

108. PACAC recommends that ‘the Government must share all the available data with local areas in as much detail as possible, ideally to patient level’ (such a recommendation as this should be read in conjunction with the need to be prepared, and think about what data this includes, and how to share it while protecting it, in advance).
109. The IfG recommends that DLUHC consults on how to reset the relationship between central and local government in England when it comes to working with data, which should take in the role of Oflog, data skills and capabilities at local level, reform of the Single Data List and the creation of a data brokering function (local government being able to ask a designated part of central government to help them find data they need) to facilitate reciprocal data sharing between central and local government. There may also be a role for the UK Statistics Authority in supporting timely data and data sharing across the nations and regions of the UK – which could be reviewed as part of the planned Cabinet Office review into the UKSA.
110. The National Preparedness Commission calls for increased inter-sector collaboration, through identifying key relationships (including localised groups) and ensuring collaboration exists (and is included in planning exercises).
111. The Blavatnik School of Government recommends that ‘the tactical ability of local government to respond to national crisis’ would be improved by investment (backed by central government) in data collection capability (and ‘additional crisis-management staff’). It suggests a comprehensive review of data collection capability across local government and other local organisations – and how they connect to central government mechanisms – could be helpful.
112. Academic collaboration was critical to the pandemic response, as shown by the various modelling groups supporting the SAGE apparatus. Future improvement might be possible. The Royal Society, for example, recommends the government should ‘explore mechanisms’ for expanding the use of Trusted Research Environments (TREs) for data that might be useful during an emergency, and considering their resilience (for example, allowing remote access and addressing skills shortages). In an earlier report, the RS’s Data Evaluation and Learning for Viral Epidemics (DELVE) group recommended that the ONS should work with the ICO to formulate a ‘data driving licence’ – a standardised qualification for data access that would allow qualified experts to get ‘rapid access’ to data with the appropriate ethical and legal training already in place. DELVE also wanted government to fund ‘interdisciplinary pathfinder data projects’ – collaborations between industries, academia and different government departments – including around nowcasting of economic metrics and mobility data.
113. **Public engagement.** The Royal Society recommends that ‘public engagement should form a core part in the development of new data policy’ and a good place to start would be evaluating previous engagement initiatives to ‘to inform a new, continual programme of engagement focused on increasing public understanding of how sensitive data and statistics are used, scrutinised and regulated’.
114. The IfG recommends that the Centre for Data Ethics and Innovation should take the lead and work with CDDO to produce guidance and resources on how to engage the public at every stage of data sharing. Government should also implement existing recommendations and otherwise explore greater transparency (for example, around DPIAs), and could also consider funding research councils to pilot particular ways of doing this. It may also need to consider having some standing capacity for such initiatives.
115. **Transparency and openness.** The government’s technical report notes that data transparency ‘helped engage the public with public health interventions’, and that data visualisations (such as those

provided by the Covid-19 dashboard) were valuable for decision makers inside government as well as the wider public.

116. The National Preparedness Commission also calls for transparency around what data is being shared under normal circumstances and what further data sharing might be expected during an emergency.
117. The Office for Statistics Regulation also underlines the importance of producers of data being transparent and engaging with the public.
118. Greater transparency, for example around data sharing agreements, could support others across government as they create new ones and provide greater insights to public servants and regulators, as well as the public, around how data is being shared across government (and what works, and what doesn't).
119. A few of the reports touch on **legislation**. On the whole, such reports acknowledge that existing legislation was largely fit for purpose and other barriers (cultural, organisational and technical) are more significant and that the urgency of data need during the pandemic overcame some of these barriers, at least temporarily. The IfG recommends the government revisits its proposed changes to legislation through the Data Protection and Digital Information (No 2) Bill – particularly relaxing requirements around Data Protection Impacts Assessments and data protection officers, which were considered useful by civil servants working during the pandemic. Legislation could be used to support better public engagement and ensure data flows during an emergency response; the Office for Statistics Regulation notes that legislation could be useful, 'where necessary' alongside investment in recommending government prioritises sharing and linking data. The Royal Society says the government should consider providing greater clarity on the data that can be collected for emergency responses, whether predictable events (such as flooding) or potential black swan events.
120. **Data literacy and political leadership.** The OSR wants senior leaders in government to be champions for high quality use of data – this requires them to have the right skills and knowledge to carry out the role. The Analysis Function, Government Statistical Service and others have done a lot of work in recent years around improving data literacy – but there are still few civil service leaders who have come from data-oriented professional backgrounds and fewer politicians (on all sides) who have engaged with data policy issues.
121. **Other useful areas** might include:
 - a. A more general review of the insight, evidence and data infrastructure and flows of government, and how it all fits together. There are many organisations, some with overlapping remits, which could risk unnecessary duplication; it is often difficult to understand what data is held where and how it can flow to the right parts of government; we do not think enough about information as one of the key underpinnings of a modern state and the different institutions and roles required to make the most of it; and we do not have an especially clear picture of where data is being shared in government and how.
 - b. Understanding the use of data at the frontline of public services and policymaking. A risk of high level recommendations is that they can fail to understand the data burdens placed on those having to collect and use data, and can feel abstract and removed from the realities of working with data.
122. **Investment in the above.** The Office for Statistics Regulation underlines that – alongside the need for leadership and collaboration to protect the independence of statisticians, and a commitment to transparency (including statistics quoted publicly by politicians being published in an accessible form) – governments should commit sufficient investment to areas such as data sharing and linking, data infrastructure, and analytical resource. The need to be willing to invest is a theme also picked up by

the National Audit Office in their recent report on digital transformation (ibid) – they note that the CDDO is laying ‘good foundations’ but express concern that its ‘small budget and headcount are already affecting the intended reforms to government central functions’ treatment of digital programmes’.

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Annex: Relevant reports and projects

Author's publications

Institute for Government

- [Data sharing during the pandemic: final report; public event](#); and six roundtable write-ups on [legislation to support data sharing](#); [the Clinically Extremely Vulnerable People Service](#); [data sharing for counter fraud activities](#); [General Practice Data for Planning and Research \(GPDP\)](#); [data sharing between national, devolved and local government](#); and [NHS Covid-19 Data Store and NHS National Data Platform](#) (December 2022 to February 2023)
- [Digital government during the coronavirus crisis](#) (November 2020)
- [The government's coronavirus data presentation is on the downside](#) (November 2020)
- [Four things government must learn from the A-level algorithm fiasco](#) (August 2020)
- [Poor chart rating for the government's coronavirus communications strategy](#) (May 2020)
- [Personal data and coronavirus](#) (May 2020, last updated September 2020)
- [Timeline: UK government, coronavirus and data](#) (April 2020 to July 2020)
- [Government use of personal data in the coronavirus response requires public debate and support](#) (April 2020)
- [Data Bites: getting things done with data in government](#) (event series, from April 2019)

Ada Lovelace Institute

- [Vaccine passports and COVID-19 status apps](#), including [Checkpoints for vaccine passports](#) (May 2021)

Open Data Institute

- [Data sharing for public service delivery: a roundtable discussion on the UK government's data protection consultation](#) (with Institute for Government, October 2021), part of [the ODI's wider response to the Data: a new direction consultation](#) (November 2021)
- [Mapping data in the UK government](#) (October 2021), including [crowdsourced document](#)

Understanding Patient Data, Wellcome

- Long read on the Covid-19 R Number (forthcoming, draft attached for reference), summarised in ['How the R number took over our lives — and what we can learn from it'](#) (December 2021)

Public Digital

- [The numbers game: Communicating data in the age of covid-19](#) (summer 2021)

UWE Bristol Data Research, Access and Governance Network (DRAGoN)

- Conference on [Covid-19: A catalyst for greater data collection and access?](#) (January 2021)

Royal Statistical Society

- Governments' statistical resources as part of [Covid evidence sessions](#) (April to July 2022)

Other

- [List of important UK government reports on data, information and open government](#), also crowdsourced from others (not fully up to date)

Other

Historical reviews of data sharing

- [government.direct: a prospectus for the electronic delivery of Government services](#), Chancellor of the Duchy of Lancaster (1996)
- [Report on the Review of Patient-Identifiable Information](#), Caldicott Committee for Department of Health (1997)
- [Modernising government](#), Cabinet Office (1999)
- [e-government: A strategic framework for public services in the information age](#), Cabinet Office (2000)
- [Privacy and data-sharing: The way forward for public services](#), Cabinet Office (2002)
- [Transformational government: enabled by technology](#), Cabinet Office (2005), and [implementation plan](#) (2006)
- [Information sharing vision statement](#), Department for Constitutional Affairs (2006)
- [Service transformation: A better service for citizens and businesses, a better deal for the taxpayer by Sir David Varney](#), HM Treasury (2006)
- [The Power of Information: An independent review by Ed Mayo and Tom Steinberg](#), and [government response](#) (2007 – [see also](#))
- [Data sharing review by Richard Thomas and Mark Walport](#), Ministry of Justice (2008)
- [Government ICT Strategy](#), Cabinet Office (2011)
- [Government Digital Strategy](#), Cabinet Office (2012)
- [Open Data: unleashing the potential \(White Paper\)](#), Cabinet Office (2012)
- [Improving Access for Research and Policy, Administrative Data Taskforce](#) (2012) – [government response](#) (2013)
- [Shakespeare review of public sector information](#) and [government response](#), Cabinet Office and Department for Business, Innovation and Skills (2013)
- [Information: To Share Or Not To Share? The Information Governance Review](#), Dame Fiona Caldicott for the Department of Health (2013)
- [Data Sharing between Public Bodies](#), Law Commission (2014)
- [Allan Review of government digital records](#) (2015) and government response, [Better Information for Better Government](#), Cabinet Office (2017)
- [Government Transformation Strategy](#), Government Digital Service (2017)
- [Data - unlocking the power of data in the UK economy and improving public confidence in its use](#), as part of the [UK Digital Strategy](#), Department for Culture, Media and Sport (2017)

- [National Data Strategy](#), Department for Digital, Culture, Media and Sport (2020)
- [Joined up data in government: the future of data linking methods](#), Office for National Statistics and Analysis Function (2020)
- [Transforming for a digital future: Roadmap for digital and data, 2022 to 2025](#), Central Digital and Data Office (2022)
- [Data saves lives: reshaping health and social care with data](#), Department of Health and Social Care (2022)
- [Better, broader, safer: using health data for research and analysis](#), Goldacre Review for the Department of Health and Social Care (2022)
- [Challenges in using data across government](#), National Audit Office (2019)
- [Digital government and e-government archives](#), Jerry Fishenden

Select Committees

- [Coronavirus: lessons learned to date](#), Health and Social Care Committee and Science and Technology Committee (October 2021) – [government response](#) (June 2022)
- [Government transparency and accountability during Covid 19: The data underpinning decisions](#), Public Administration and Constitutional Affairs Committee (March 2021) – [government response](#) (May 2021)

Ada Lovelace Institute

- [Learning data lessons: data access and sharing during COVID-19](#) (January 2021)
- [The data divide: Public attitudes to tackling social and health inequalities in the COVID-19 pandemic and beyond](#) (March 2021)
- [The rule of trust: Findings from citizens' juries on the good governance of data in pandemics](#) (July 2022)

ODI

- [Covid-19: Building an open and trustworthy data ecosystem](#) (April to December 2020)
- [Mobility data sharing during the Covid-19 pandemic – Research from Cuebiq and The GovLab](#) (March 2021)
- [More](#)

Royal Society

- [Data Readiness: Lessons from an Emergency, DELVE initiative](#) (November 2020)
- [Creating resilient and trusted data systems](#) (February 2023)

Other

- [Protecting and supporting the clinically extremely vulnerable during lockdown](#) (February 2021)
- [The data flows of COVID-19](#), medConfidential (March 2021 – [see also](#))
- [Initial learning from the government's response to the COVID-19 pandemic](#), National Audit Office (May 2021)
- [Directors of public health and the Covid-19 pandemic: 'A year like no other'](#), The King's Fund (September 2021)
- [The Data-sharing Imperative: Lessons from the Pandemic](#), National Preparedness Commission (January 2022)
- [Crisis Preparation in the Age of Long Emergencies](#), Blavatnik School of Government (March 2023)
- [The Treasury during Covid: What lessons can be learned from the pandemic?](#), Institute for Government (April 2023)

UK government

- [Addressing trust in public sector data use](#), Centre for Data Ethics and Innovation (July 2020)
- [Information sharing to support direct care survey report](#), National Data Guardian (August 2020)
- [Polling indicates growing public understanding about importance of using health and care data](#), National Data Guardian (October 2020)
- [Local government use of data during the pandemic](#), Centre for Data Ethics and Innovation (February 2021)
- [Improving health and social care statistics: lessons learned from the COVID-19 pandemic](#), Office for Statistics Regulation (October 2021 – [January 2023 update](#))
- [COVID-19 and information rights: reflections and lessons learnt from the Information Commissioner](#), Information Commissioner's Office (November 2021)
- [Technical report on the COVID-19 pandemic in the UK](#), for Department of Health and Social Care (January 2023)