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Data sharing during coronavirus: lessons for government

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Summary

The Covid-19 pandemic represented the "high watermark of data use" by government, according to the UK government's *National Data Strategy* (2020).[1] Data provided "a lifeline": organisations inside and outside government being able to "share vital information quickly, efficiently and ethically… not only saved countless lives" but "enabled us to work from home, keep the economy running and stay connected with loved ones".[2] In this view, different parts of government successfully sharing data with each other and the private sector to inform public health strategies and build new services (such as providing food and medicine to vulnerable people, and preventing businesses from collapsing) demonstrated the truth of long-standing claims that better use of data could lead to better operational and policy decisions and better public services.

A 2021 report by the House of Commons Health and Social Care Select Committee and Science and Technology Select Committee was less sanguine. The parliamentarians thought it "evident that the sharing of granular data is critical to an effective response to an emergency",[3] but argued that "a country with a world-class expertise in data

analysis should not have faced the biggest health crisis in a hundred years with virtually no data to analyse".[4] The committees heard about delays in sharing results from epidemiological modelling, and how establishing NHS Test and Trace as a new organisation outside the health care system created technical challenges that hindered the sharing of positive infection cases and their locations with local authorities.

The government says "it is vital that we make the most of what we have learnt" during the pandemic about sharing data effectively to benefit society and help people – for example, by using it to provide better public services.[5] To do this it has introduced the Data Protection and Digital Information Bill to parliament to change some of the rules around sharing personal data, is consulting on data sharing across departments to help citizens access public services more easily, and is undertaking several other initiatives designed to support the better use of data in policy decisions and public services across government including the Integrated Data Service.[*,6]

But has government learnt the right lessons about sharing data – particularly personal information about citizens – during the pandemic? And are ministers and civil servants making the most of data while mitigating the risks?

During the summer of 2022, the Institute for Government, in partnership with Scott Logic, convened six roundtables to discuss case studies of data sharing during the pandemic. The roundtables covered:

- Legislation to support data sharing, including the enabling role of the Data Protection Act 2018 and Digital Economy Act 2017
- The creation and operation of the clinically extremely vulnerable people service, which helped people who were 'shielding' access critical food and medical supplies
- How data sharing supported counter fraud activities, including in Covid business support schemes
- Sharing of locally aggregated Covid case rate and vaccination uptake data between national, devolved and local government
- The General Practice Data for Planning and Research (GPDPR) initiative and lessons for earning public trust in data sharing
- The creation of the NHS Covid-19 Data Store to collate a variety of health care datasets to inform resource planning and improve the performance of the health care system.

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[*] The Integrated Data Service is being created by the Office for National Statistics to underpin the National Data Strategy.

This report synthesises some of the key themes and lessons that emerged from across those roundtable discussions and write-ups. They include:

- **The legislation – including the Data Protection Act 2018 and UK GDPR – underpinning data sharing was firm but sufficiently flexible to allow government to respond** quickly to the crisis of the pandemic. Given this, the government should be careful in its pursuit of planned reforms including the Data Protection and Digital Information Bill; the most significant challenges with data sharing identified by our roundtable participants were not legislative, but cultural and organisational, meaning further legislation may fail to resolve (and might instead distract from) the problems that actually posed a barrier to effective data sharing.
- **Data sharing benefits from having a clearly articulated purpose**, not only as a necessary legal requirement for data sharing, but also to enable those involved to identify the best technical solution, facilitate engagement with senior leaders, and provide clarity to the public about how their data will be used. For example, knowing the purpose of the NHS Covid-19 Data Store was to equip decision makers with high-quality data from across the health system allowed the project team to prioritise datasets and enable access to data and analysis for decision makers in multiple organisations. Roundtable participants repeatedly stressed that knowing the purpose of data sharing helped avoid scope creep and additional data sharing requests that would go beyond the initial agreed purpose.
- **Multi-disciplinary teams were essential** to bring together the range of expertise (legal, information governance, technical, policy) needed to work through policy and technical choices. On the clinically extremely vulnerable people service, information governance, legal, data protection and technical experts worked together to design a secure data repository that would satisfy UK GDPR and the common law duty of confidentiality to underpin the service. Creating a new data service is not a linear process and a multi-disciplinary team was better able to troubleshoot issues in advance that supported the development of a functional service.
- **Data sharing successes during the pandemic resulted from an unusually urgent need to build new services quickly**. This would have been easier had more organisations been prepared to share data, either through established data sharing frameworks or through building relationships and trust in mutual data practices. There were numerous examples of data not being shared where it could have been of real benefit – for instance, local data on case rates and vaccination uptake. Relevant data was held by national and devolved government, local authorities and NHS trusts, and the absence of such agreements and frameworks created delays in its sharing. Advance preparation, such as a pre-agreed data sharing framework like the Wales Accord on the Sharing of Personal Information, would have facilitated the sharing of data.

- **Technical difficulties sometimes slowed data sharing activity, but could usually be overcome**. Difficulties arose either through incompatible or separate IT systems needing to share data, or due to poor data quality. UK government, through the Central Digital and Data Office (CDDO), has set data standards but these are not always adhered to when creating or managing data until it is needed for sharing. This was a particular issue during the pandemic: using address data without unique property reference numbers (UPRNs) made delivering support to vulnerable households or knowing where positive Covid infections were located difficult.

- **Engaging the public around how their data is used is critical for success**. It can help build trust about what data is being used for and improve the design of products and services using data, particularly personal data. This trust is critically important if people are being asked to support the sharing of personal information, where fear of misuse is especially acute. For example, in General Practice Data for Planning and Research (GPDPR) – a scheme to share patients' health data – a lack of consultation and consent led to millions opting out of their data being used. Polling demonstrates that if effective steps are taken to build trust then the public are open to sharing.[7]

Participants in our roundtables were concerned that the clarity of purpose and political imperative that supported successful data sharing projects during the pandemic might be lost as government moves from emergency operation back to business as usual. Others felt a sense of crisis might be a recurring feature of public administration over the next few years (for example, in tackling rising energy prices and the cost of living crisis) and that this might continue to drive data sharing in the public interest. But most agreed that the most sustainable way of ensuring that the benefits of data sharing during the pandemic continue would be to capture and share the most effective behaviours and ways of working, and the legislative, cultural and organisational underpinnings of these, as we have done in this project.

A note on the terminology and principle of data sharing

We refer to 'data sharing' throughout this report and the other roundtable summaries. That is the language used by many people working within government over the last few years, as well as by many participants at our roundtables.

However, the term 'data sharing' makes several assumptions. These include data 'belonging' to particular parts of government in the first place, which then needs to be moved into other systems to be considered 'shared'. This may encourage departments to hoard data as they treat it as their own or raise concerns about who is ultimately responsible for the data. Instead, other terms such as 'data access' or 'data availability' are gaining prominence and might be more technically accurate, as shared data can be accessed and analysed within its host environment, removing uncertainty about data ownership.

There was often a sense at the roundtables that data sharing is inherently beneficial and it is therefore only a good thing if it is made easier and quicker. This reflects a widely held view among data professionals that the risks and associated fear of sharing data had previously stymied attempts to share data more easily and quickly. This view was challenged and disrupted by the pandemic. At multiple roundtables, participants suggested there was a growing need to consider the risk of not sharing data – a concept raised elsewhere by figures including John Edwards, the information commissioner,[8] and the National Data Guardian (which "advises and challenges" the health and care system on its use of people's information).[9]

It is certainly the case that there is a public good in the motivation behind many of the examples in this project and that data sharing supported the effective design and delivery of critically important services. However, there are good reasons why data sharing should include some friction and be closely scrutinised. Personal data is particularly sensitive and there is a real risk of harm (as we saw with the algorithms used to award exam grades during the pandemic) if things go wrong.[10]

The government cannot take public support for data sharing for granted even where it thinks the benefits are self-evident. According to polling by the National Data Guardian, while there was high public support for the sharing of health and care data during the pandemic, 70% of people thought data sharing rules should return to their pre-pandemic form.[11] The Centre for Data Ethics and Innovation also recorded a fall in public trust in government's use of data over the last year,[12] but as a recent Royal Society report has also found, better public engagement and protections around data usage can help sustain public trust.[13] Public attitudes to data sharing can be highly dependent on the particular context and use, where controversial uses of data sharing – such as the government allowing police to request health data despite assurances this would not be allowed[14] – could damage public trust for data sharing in general. This underlines the centrality of transparency, accountability and public engagement required for effective data sharing, along with the other key themes identified in this report.

Recommendations

The government should reconsider several of its proposed changes to the Data Protection and Digital Information Bill.

The Data Protection and Digital Information Bill would remove the requirement for several measures that were highlighted as useful by roundtable participants, such as data protection impact assessments (DPIAs) and data protection officers. The bill should retain these aspects and consider how to ensure data flows as part of government's emergency planning.

In addition, the bill should strengthen provisions around citizen engagement. This could include mandating public engagement and advisory groups of citizens and subject experts around data sharing projects in the public sector.

The relationship between different levels of government in the UK around data needs to be reset.

The Department of Levelling Up, Housing and Communities (DLUHC) should consult on a strategy for improved working around data between central and local government in England.

This should include:

- The role of the proposed Office for Local Government (Oflog). The levelling up white paper pledged a new independent body, focused on strengthening local data for citizens and local leaders. But Oflog could play a greater role in ensuring local leaders have the tools and capabilities they need to obtain and use data in their decisions and operations, in tandem with (welcome) initiatives such as the DLUHC Spatial Data Unit and ONS subnational strategy.
- Reform of the single data list. This outlines a list of datasets that central government requires local government to provide, on everything from school capacity to housebuilding to conservation and biodiversity; local authorities do not have to provide something if it is not on the list. This could provide a focus for discussions about data flows between different levels of government – not just what central government demands from local government, but reciprocal flows heading the other way.
- A data availability or brokering function within DLUHC. If local government bodies need data from anywhere in central government, it would be helpful to provide a single point of contact to ask for it, with the brokering function then being responsible for finding the right contacts within central government. This would also provide strategic insight into local government data needs and enable central government to understand whether particular datasets should be made more widely available.

The UK Statistics Authority, the non-ministerial department responsible for the statistical system, could play a role in supporting data sharing and co-operation between public bodies in different parts of the UK. This should be explored in the forthcoming review of its work announced by the Cabinet Office, which could include convening the different nations and regions of the United Kingdom, and undertaking further work (for example, on timeliness of data releases) to support better working between different public sector organisations across the UK.

A data sharing framework should be established by DLUHC and CDDO in collaboration with local authorities, directors of public health and other relevant departments across local government and public services. This would complement ongoing work to improve data flows in response to an emergency by the National Situation Centre and the Cabinet Office and be designed to offer a pre-agreed set of data sharing principles into which organisations could opt without needing to rely on the Civil Contingencies Act. This would improve data sharing closer to the point of delivery at local authority level, and potentially enhance public service performance.

The Central Digital and Data Office should produce a data sharing 'playbook' to help public servants building new services founded on the use of data.

Such a playbook should aim to minimise barriers to civil servants establishing new data sharing agreements for public benefit, while respecting the rights and views of the public and aligning with the Information Commissioner's Office (ICO) guidance. It should include:

- Templates for standard documents critical to data sharing processes, such as data sharing frameworks or data protection impact assessments (DPIAs)
- Links to guidance about relevant legislation, such as the Digital Economy Act and UK General Data Protection Regulation
- Links to relevant documents already produced by the CDDO, the Government Data Quality Hub, the Government Statistical Service, the Office for National Statistics (ONS), National Audit Office (NAO), and the ICO
- A guide on how to engage the public in discussions about data sharing (see next recommendation, below)
- Resources to help colleagues understand the practicalities of data sharing, such as how to scope a new project or service, advice on which professions to engage at different stages of a project, the steps necessary to establish a data sharing agreement, and case studies.

The government should produce guidance and other resources on how to engage the public at every stage of data sharing.

The Centre for Data Ethics and Innovation (CDEI) – which already leads work on public attitudes towards data and technology, and helps co-ordinate the cross-government public attitudes to data and AI (PADAI) network – should lead this work, collaborating with CDDO as it develops the playbook above. The guidance and resources could include a toolkit, case studies and research on what works or even a standing team ready to support public engagement on data sharing across government. It should also draw upon guidance and resources from elsewhere in government, such as the ICO, National Data Guardian and the UK Statistics Authority and its component parts (the ONS or Office for Statistics Regulation).

In addition to central resources, government could take additional measures to better support public engagement and communication on data sharing, including:

- Funding research bodies, such as UK Research and Innovation, to research and pilot public engagement activities around data in order to understand what models work in different circumstances and disseminate their findings

- Implementing existing recommendations on transparency and talking to the public (e.g. the recommendations of the Goldacre Review)*, and mandating greater transparency (e.g. around plans and DPIAs). Transparency around these documents would mean they could be analysed and communicated by regulators, researchers and civil society to understand best practice and highlight common challenges.

Lessons for future data sharing

Legislation

The government is proposing to amend existing data protection law through the Data Protection and Digital Information Bill, which is expected to return to parliament at some point in 2023 (having been delayed by changes of prime minister and with speculation that the government could make some changes before it returns). The bill has been framed as delivering some of the "benefits of Brexit" through creating a "pro-growth and innovation friendly data protection regime";[15] Brexit allows the UK to diverge from the European version of GDPR – the General Data Protection Regulation, which sets out the principles, obligations and rights around the processing of personal data.** The government believes its reforms will support data sharing through widening the grounds on which data can be shared while removing what it sees as onerous requirements on organisations – such as the need to produce data protection impact assessments and to have a data protection officer. The government believes these measures will reduce the burden on organisations and increase innovation.[16]

But a key lesson from the pandemic has been that existing legislation is largely fit for both emergency and non-emergency situations, and allowed the government to respond swiftly when data sharing was required. Roundtable participants felt existing legislation, such as the Digital Economy Act and Data Protection Act (which incorporated GDPR into UK law) and the data sharing code and data sharing hub from the ICO,[17,18] provided a guide to what is possible with data sharing and how to do it. These created a stable environment in which to operate with confidence, allowed good practice to be scaled up, provided something 'solid' for civil servants to point to so that data could be shared, and provided continuity as leadership changed and priorities shifted. The Data Protection Act and UK GDPR provided sufficient flexibility and adaptability; DPIAs helped enable the right conversations about data sharing, forced public servants to address 'hard questions' (such as the needs of individuals versus the organisation's need to process their data) and helped enable greater transparency and accountability with the public able to scrutinise plans. In the experience of one roundtable attendee, the Digital Economy Act helped speed up the establishment of new data sharing agreements – from between six and 30 months to something closer to four weeks when working as fast as possible.

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* These include being honest about the shortcomings of existing mechanisms – like pseudonymisation and trust – to protect data and ensuring 'high-quality' patient and public engagement in research projects.

** However, divergence could threaten the UK's data adequacy with the EU. This is a status that allows cross-border data flows between the UK and the EU, because the EU currently considers the UK regime to provide an acceptable level of data protection.

The government appears to acknowledge the utility of existing legislation, too. In the foreword to the 2020 *National Data Strategy*, Oliver Dowden – then secretary of state for digital, culture, media and sport – wrote that "governments, businesses, organisations and public services were able to share vital information quickly, efficiently and ethically during the pandemic [which] has not only saved countless lives, but has enabled us to work from home, keep the economy running and stay connected with loved ones during a period of unprecedented disruption".[19] Even where emergency measures, like control of patient information (COPI) notices, were used to more quickly establish data sharing agreements, they did so within the principles, processes and frameworks of existing legislation.

Existing legislation is not perfect. For example, participants involved in building the NHS Covid-19 Data Store noted they had to spend some time reconciling contradictions between different health acts around data sharing, while participants in our legislation roundtable noted good intentions (protecting citizens' privacy) could lead to unintended consequences (cookie pop-up banners on websites that do not work well for the public or businesses – the Data Protection and Digital Information Bill proposes to reform this). The new bill could create some opportunities for better data sharing: roundtable participants thought it was a chance for government to launch a new conversation about the benefits of sharing data, rather than the fear often associated with it.

But the new bill could also destabilise the existing legal environment, which is still bedding in, and remove some critical protections and processes. Data protection officers and DPIAs were frequently highlighted by participants in our roundtables as useful, and remain recommended by the ICO as a useful tool even when not mandatory.[20] Relying on the new bill to improve data sharing may also incorrectly focus attention on legislative process as the key to better data sharing across government. Our research found that legislation cannot solve the most critical challenges: a constant theme of our roundtables was that cultural and organisational barriers, not legislative ones, are the most substantial. Participants said these include a lack of awareness by civil servants and politicians about what data sharing powers allow them to do leading to underuse (particularly of powers in the Digital Economy Act), a lack of data literacy in senior civil servants and politicians, and different departments having different levels of capacity, capability and willingness to share data.

Purpose

The establishment of data sharing agreements requires a clear project purpose to be successful. Participants at multiple roundtables highlighted how a clear purpose enabled planning for data protection requirements and completing data protection impact assessments.[21] Knowing the purpose of the exercise allowed teams to assign appropriate data controllers and make decisions about data storage and security, in turn reducing technical uncertainty in the build. Fundamentally, the project purpose also sets out the lawful basis under UK GDPR, which facilitates the data to be shared.[22]

The team operating the clinically extremely vulnerable people service used the project purpose – which was to quickly provide access to food and medicine to the clinically vulnerable – to agree critical decisions. For example, the purpose made it clear that the service did not need to know what health conditions made individuals eligible for support, which allowed the team to pursue data minimisation techniques,[23] and knowing supporting services needed the address information for each individual meant the team knew to prioritise data security in its technical build.[24]

Knowing the purpose is essential for identifying the legal basis for data sharing. The service team initially intended to use 'public task' – which allows specific data sharing if in the public interest – for the service.[25] But as the service needed to handle personal health care information, the team worked with the ICO to minimise legal concerns,[26] and ultimately relied on the COPI notices that provided a time-limited 'Covid-19 purpose' for the sharing of confidential medical information to protect public health and provide health care services.[27] The clear purpose also set limitations about how data could be used and for what time period, strengthening public trust in how the service was using personal medical information with supermarkets, and gave the project leaders confidence to refuse additional data sharing requests. Roundtable participants were clear that data sharing success relied on the project team knowing the purpose of the project.

Multi-disciplinary teams

Having the right people in the room – spanning technical, legal, information governance and policy disciplines – from the start was a critical success factor when rapidly establishing new public services dependent on data sharing. Multi-disciplinary teams benefited from having a combination of specialisms together from the outset to troubleshoot potential issues before they become problems.

The clinically extremely vulnerable people service benefited from having direct access to information governance and legal experts when making decisions about how to store personally identifiable medical information in a format that would allow onward sharing with local authorities, social care providers and supermarkets.[28] The design team were also able to quickly react to policy clarifications, such as how people could opt out of the service or what information could be shared with supermarkets to allow them to match with existing customer databases. These policy points impacted the technical build – for example, the development of an effective customer management functionality once the clinically extremely vulnerable people service was broadened to allow people to register or opt out of support.[29] This was facilitated through the technical and policy professions working together and collaborating throughout the project.

Cross-organisational working

The pandemic helped overcome one of the common challenges to data sharing – that persuading organisations to share data with each other can be difficult. An organisation holding data that another organisation wants must take on an administrative burden in preparing the data, and must accept legal risk and responsibility for sharing data for the agreed purpose, for what can feel like little gain. The pandemic changed this. The urgency and clear importance of establishing new data sharing agreements meant organisations were motivated to share data more easily than usual.[30]

In some cases, hesitancy persisted due to (for example) uncertainty about which organisations would be accountable for decisions based on shared data, or sensitivity about how data might be interpreted in future spending allocations by the Treasury. Hesitancy was overcome through senior leadership interventions or the quick building of close working relationships and goodwill, as was the case for directors of public health working with local NHS trusts to understand local variations in case rates and vaccination uptake.

Data relationships between national and local government

There were some difficulties sharing data between national and local government. Data, particularly individual-level data, was slow to be provided to councils, even after the publication of a COPI notice.[31] Local leaders and directors of public health in England wanted access to epidemiological modelling results, locally aggregated and patient-identifiable datasets to help guide their pandemic response measures, for instance about where case rates were rising, or vaccination rates were low. Once local health leaders had access to patient-identifiable data on infections, they were able, with their local knowledge, to match localised outbreaks with specific workplaces and intervene to improve public health measures. Directors of public health strongly felt they shouldn't have had to explain repeatedly why they needed access to such data, and that central government should have had an understanding of their role as part of the pandemic response, with specific statutory duties, which required immediate access to good quality data.[32]

There were several reasons for the delayed sharing of information, but a recurring point was that national government created new systems, such as NHS Test and Trace, without plans for how to share data more broadly and saw "local authorities [as] an afterthought in the designs for data sharing".[33] Because these new systems were outside the public health system, it took time to establish new data sharing agreements and overcome any technical difficulties making data compatible across systems. Responding to select committee criticism of the time taken to share national data with local authorities, the government said that "arrangements should be established and tested to allow immediate flows of data between bodies relevant to an emergency response with a mechanism to resolve immediately and decisively any disputes".[34]

Successes came when national and local government worked together. 'Teach out' sessions were run by the Ministry of Housing, Communities and Local Government (MHCLG) to help local authorities handle incoming data for the clinically extremely vulnerable people service, upskilling some local authorities to handle frequently changing data. Feedback from local authorities eventually led to MHCLG improving the quality of address information by adding UPRNs to datasets, better enabling local authorities to manage and use the data. Similarly, the DLUHC Covid-19 Challenge Fund formed a community of local data leaders who could share best practice and ideas during the pandemic in addition to funded projects to improve local government's response to the pandemic.[35] Success ultimately relied on collaboration between organisations to identify problems or concerns with the data sharing agreements being used in order to provide clarity of improvements to practice as required.

Preparation

The pandemic demonstrated the challenge of urgently agreeing data sharing standards when establishing new projects and services. Given data will be an essential part of any future emergency response, it is important to plan now for how government will facilitate future data sharing.

This will likely require the continuation of existing or recently established data assets, such as the NHS Covid-19 Data Store via the Public Health Data Asset and the National Data Platform.[36,37] These have benefited from the creation of a shared set of definitions (an ontology) for health care data during the creation of the NHS Covid-19 Data Store. The ontology describes the data formats and metadata requirements needed to facilitate data sharing between different IT platforms and software providers, which will minimise technical barriers. Establishing agreed definitions and formats will be needed to best prepare for future data sharing arrangements.

Beyond NHS data, frameworks could be established for other future data sharing agreements. The Wales Accord on the Sharing of Personal Information (WASPI) was established in Wales across health and social care, local authorities, emergency services, education providers and other organisations to help them meet data protection responsibilities.[38] This took multiple meetings and workshops over many years to formulate, but provides a common set of principles for the sharing of personal information, which greatly facilitated the Welsh government's response during the pandemic. The framework reduces some of the imbalance in risk perception often associated with establishing new data sharing agreements, reducing any legislative barriers preventing data sharing.

An alternative method for building trust and confidence in data sharing practices between multiple organisations would be to run smaller proof of concept projects. This has been successfully used to trial and establish public–private data sharing by the Joint Money Laundering Intelligence Taskforce and could be used to provide joint learning opportunities to different types of organisations that would like to share data in the future. Alternatively, trusted research environments (TREs) or regulatory sandboxes[*] could be used by multiple organisations to practise or rehearse their data sharing capabilities to improve their emergency readiness.[39]

Public engagement

A strong theme throughout the project was the need to engage the right people at the right time. This presented itself in various forms – having the right people from across different departments and disciplines in the room from the start, or ensuring reciprocal relations between local and central government. But arguably most prominent was the need to engage the public at every stage of a data sharing project, from idea to implementation.

Participants in our roundtables thought engaging the public on how their data is shared and used across government had several benefits. Such engagement was vital for earning public trust in a project, testing the limits of what the public was willing to accept and allowing innovative uses of data. Engagement should ultimately lead to a better product or service and avoid a situation, like General Practice Data for Planning and Research (GPDPR), where officials had to pause the project owing to public controversy. A loss of trust in a data sharing project could cause it to fail: GPDPR caused the number of patients opting out of their data being available for use beyond their individual care to almost double from 2.7% to 5.4% of people in England, meaning around 1.5 million fewer patients willing to share their health care records for medical research, reducing the amount of information available to UK researchers.[40]

Roundtable participants working with health data were also concerned that negative public responses to some data sharing projects across the public sector could undermine trust in their projects. Public opinion can vary when different organisations use the same dataset: for example, the public would accept the use of wastewater testing results at a postcode level to guide public health interventions but would not accept that data being made available to law enforcement agencies.[41]

Engaging the public can feel challenging for several reasons. The public is not homogenous – different people will have different views about the sharing of data in different contexts, which may not lead to an easy consensus. Indeed, the same person might have different views on the same situation – as a member of the public versus as a patient. Public servants might expect public views to be negative, but contributors to several roundtables argued that views were likely to be nuanced, informed and could often be positive. Public engagement before the passage of the Digital Economy Act, for example, found the public more willing to say "yes, but" or "maybe" to proposed data sharing agreements rather than an outright "no". Even if views are negative, it is better to understand that at an early stage before a project has gone too far.

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[*] A regulatory sandbox is a service where organisations can work with the regulator to support the development of new systems that use personal data in novel ways.

Greater transparency can pose challenges – leading to headlines that pose a communications challenge to public sector organisations – for example, the NHS Covid-19 Data Store's openness about the private companies involved in the project led to several stories in the press. It can also be hard work for public servants to reach some of those likely to be affected by data-informed decisions rather than those (like tech companies or civil society organisations) likely to lobby on legislation or particular projects, and to scale engagement in a manageable way if lots of people want to be involved. In fact, public willingness to be involved in a consultation on the use of wastewater data and the number signing up to Covid symptom apps showed how much public interest there is in the use of data – and readiness to share data where there is a clear public good.

But roundtable participants felt strongly that the hard work was worth it for the benefits public engagement could bring, in trustworthiness and effectiveness, and had several pieces of advice for how public sector organisations should engage citizens.

They should:

- involve the public at every stage of a project (from conception to completion)
- consider the different forms of engagement that might be appropriate, from conversations and roadshows, to public advisory boards, to co-production
- engage the public around particular policies and domains, and not around 'data' – what the data will be used for and what the benefits and risks of doing so are, rather than abstract discussions
- be honest about any risks and how they will be addressed (which should include accountability mechanisms, such as complaints and sanctions).

Doing public engagement well requires effort, time and long-term building of capacity to ensure discussions are "really meaningful, credible [and] legitimate".[42] Several examples that government could learn from were cited during the roundtables, such as ADR UK's public engagement strategy, HDR UK's public advisory board, or the work of OpenSAFELY or Genomics England.

Conclusion

Lessons learned about data sharing in government during the pandemic should have benefits for the public beyond the crisis, including better policies informed by data and public services that are more personalised, more targeted at those in need and more seamless to use. The pandemic showed what can be achieved and highlighted how a clear purpose and urgent need could overcome some of the traditionally cited barriers to data sharing. But it also showed which barriers remain to data sharing in the public interest.

Our recommendations and the other lessons that emerged from the individual roundtables suggest how some of these barriers can be overcome, while maintaining and introducing key protections for the public that will help earn trust and ultimately provide support for the effective and ethical use of data for the public good by government.

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Appendix

This synthesis report is informed by six roundtables, supplementary interviews and desk research undertaken by the Institute for Government in summer 2022. Each roundtable brought together public servants and others involved in particular case studies or thematic areas, to explore what had worked well, what could have worked better and what lessons government should learn for the future.

Each roundtable was held under the Chatham House Rule: nothing anyone said is attributed to them or their organisation, unless they asked for it to be.

A write-up of each roundtable and video and audio of a public event discussing the project is available on the Institute for Government website. The discussions do not represent the views of the Institute for Government.

- Legislation to support data sharing
- The Clinically Extremely Vulnerable People Service
- Data sharing for counter fraud activities
- Data sharing between national, devolved and local government
- General Practice Data for Planning and Research (GPDPR)
- The NHS Covid-19 Data Store and NHS National Data Platform.

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