



Office for
Statistics Regulation

Improving health and social care statistics: lessons learned from the COVID-19 pandemic

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The role of the Office for Statistics Regulation

As an independent UK-wide regulator, we are in a unique position to take a broader look at issues of importance to society and to make the case for improved statistics across organisation and Government boundaries. This is supported by our ability to convene, influence and highlight best practice from other sectors.

We want to ensure that statistics provide a robust evidence base for national and local policy development and decision making. We champion the need for statistics to support a much wider range of uses, including, by charities, community groups and individuals. They should allow individuals and organisations to reach informed decisions, answer important questions, make the case for change or hold government to account.

Introduction

The COVID-19 pandemic reinforced the vital role that data and statistics play in our society. They have been crucial for making operational decisions to manage the demands on health and care services, and essential for understanding implications for public health. There has been a huge public appetite for data and statistics, to support individuals to reach informed decisions and hold their governments to account.

It is clear that we will be living with COVID-19 for some time to come – this will require health and social care services to continue to manage and respond to increased pressures, and the long-term impact of COVID-19 on public health will need to be understood. It is also the case that many of the challenges society faced before the pandemic remain today – improving social care systems, tackling inequalities in health outcomes, and understanding mental health and wellbeing.

For all these reasons it is crucial that statistics about health and social care are trustworthy, of high quality and valuable. While society continues to face challenges from the pandemic, it is important to learn lessons from the experiences so far – particularly at a time when governments are starting to set out their plans for coming out of the pandemic. To support this learning, we carried out a review of health and social care statistics during the pandemic. To inform our review we spoke to statistics producers (referred to as ‘producers’ from now on) in governments and public health bodies across the UK. We also spoke to data providers and users of health and social care data. Building on our [State of the UK Statistical System report](#) published in July 2021, this review explores the lessons learned for health and social care statistics in more detail. Our aim in this review is to complement recent work by others such as the [Royal Statistical Society](#), [Full Fact](#), the [Health Foundation](#), and the [National Audit Office](#).

Summary

Our objective is to promote statistics that serve the public good. We want to see health and social care statistics which command public confidence and enhance public understanding. The pandemic has highlighted the need for statistics on public health, social care, and government interventions, as well as the importance of a statistical system which is responsive to emerging issues. It has also demonstrated the impact that well-communicated statistics can have on society, informing both governments and citizens.

The efforts of those involved in producing health and social care statistics in response to the pandemic have been remarkable. Producers worked quickly and collaboratively, in many cases overcoming challenges which would previously have seemed insurmountable. They provided governments with daily reporting, at pace and under considerable pressures, and demonstrated a clear commitment to providing the public with valuable information. As a result, there has been unprecedented public engagement with health and social care data. There are

positive lessons for the whole of the UK's statistical system in the speed, flexibility and collaborative approach taken, including increases in data and resource sharing between organisations. There are also positive lessons to be learned in the communication of statistics and data, for example through the publication of clear and visually engaging outputs which have attracted, at their peak, [millions of daily views](#).

However, the pandemic has also drawn attention to existing problems, and created new challenges, for health and social care data. These have resulted in gaps in, and delays to, important information. It has not always been clear where users can find the information they need or which data they should use. Building on the achievements of the pandemic and overcoming existing challenges will require:

- Strong leadership and collaboration to protect the independent role of government statisticians and create a coherent picture for users
- A commitment to transparency to ensure that statistics and data quoted publicly are published in an accessible form
- Governments to commit sufficient investment, for example in data sharing and linking, data infrastructures, and analytical resource

Our review identified ten lessons which support these objectives. These are grouped under five themes which we consider central to a strong statistical system: transparent and trustworthy; responsive and proactive; collaborative; clear and insightful; and timely.



Transparent and trustworthy

Lesson 1: Transparency is essential for building public trust in statistics and retaining public confidence in government decisions. *To demonstrate trustworthiness, statistics producers must be able to use their unique ability to act independently from the political process.*

Throughout the pandemic we have [advocated for transparency](#) of, and equal access to, data used in government decision-making. Our [expectations for transparency](#) apply regardless of how data are categorised. For many who see numbers used by governments, the distinction between official statistics and other data, such as management information or research, may seem artificial. Therefore, any data which are quoted publicly or where there is significant public interest should be released and communicated in a transparent way.

The importance of public confidence in government decisions has been evident throughout the pandemic – to support confidence in, and therefore compliance with, lockdown restrictions, self-isolation rules or the vaccination programme. Government statisticians are uniquely placed to demonstrate independence from the political process and build public trust in data which underpin these decisions. To do this, they must be given the freedom to make independent decisions and to challenge the misuse of statistics. Ministers and officials who understand the value of statistics and the expectations of the [Code of Practice for Statistics](#), are better able to proactively support producers to demonstrate transparency and trustworthiness. The [Ministerial Code](#) sets the standards of conduct expected of UK Government ministers and requires them to be mindful of the Code of Practice for Statistics. This requirement is also reflected in the [Scottish](#) and [Welsh](#) Ministerial Codes and the [Northern Ireland](#) Guidance for Ministers. The Public Administration and Constitutional Affairs Committee recently [asked for the Ministerial Code to be strengthened](#) to require Ministers to abide by the Code of Practice. In [response](#) the UK Government reiterated its commitment to transparency and its aim to publish all statistics and underlying data referenced publicly, in line with the Code of Practice.

We recognise that there are challenges when releasing new data at pace. During the pandemic, systems were introduced rapidly in response to urgent data reporting needs. Producers had to find an appropriate balance between transparent public reporting and demands to provide important internal information to inform government and health body decision-making. The rapid release of information to the public was more challenging in organisations which did not have established publishing processes for some situations, such as releasing ad-hoc data alongside ministerial statements. Some organisations also found that the time taken to check the implications of publication for other producers could lead to delays. More regular data sharing and linking, and closer collaboration between producers, would help them to respond to these situations more quickly.

Overall, we consider that health and social care statistics producers across the UK demonstrated a clear commitment to transparency through their efforts to put a huge amount of valuable information in the public domain – from data on COVID-19 cases, deaths, and hospitalisations to information about public health programmes, such as vaccinations, or contact tracing. The work by analysts to [improve data presentation](#) and [publish data](#) alongside daily Downing Street briefings demonstrated the importance of allowing experts to use their skills to enhance transparency. The [additional data and information workbook](#) published by the Scottish Government allowed for the rapid release of ad-hoc data to ensure equal access to figures used in ministerial statements.

We found that there were several ways in which producers were supported to play this important role. For example, well-established senior statistical roles within the Scottish Government and Public Health Scotland helped to ensure a common understanding of the value of statistics and data, and the standards they should meet. Building strong relationships with policy colleagues was key to developing this understanding. We have often highlighted with producers that sharing their plans for statistics with the public improves transparency and therefore enhances trustworthiness, even if these plans are tentative and later change. We have seen good examples where this has been done, such as for [vaccination statistics in Wales](#) and [NHS England Test and Trace statistics](#). We also saw the benefit of introducing formal processes for the rapid release of information at the Department of Health and Social Care, which were developed by learning from practices in other departments.

However, we have often had to intervene, both publicly and privately, when data about COVID-19 have not met expectations around accessibility or transparency. For example, we have intervened when figures quoted by ministers or government officials were not publicly accessible (such as [those used at press conferences](#)), or when poor use and presentation of data risked undermining public trust (such as on [testing figures](#)). Delays to, or gaps in, published data have often resulted in accusations that governments cherry pick or manipulate data – we have seen this in the media and on social media, as well as through [concerns raised with us](#). We have also heard frustrations from some producers who felt unable to do their jobs effectively and make the final decisions about data collections or publications. There can be many reasons for these issues, including pressures on analytical resource and delays to sign off or publication processes. During autumn 2021 we will be building on our work around the importance of transparency with a series of engagements and outputs to highlight our expectations.

Recommendations:

- The principles of the Code of Practice and our [expectations on transparency](#) should be followed for any analysis published by governments. Producers should consider [voluntary application](#) of the Code of Practice, and consider requesting a rapid review by the Office for Statistics Regulation, for data which are not official statistics.

- Organisations should ensure that processes exist for releasing data quickly and transparently. This will be especially important for new bodies and organisations, such as the UK Health Security Agency.

Lesson 2: Senior leaders within governments can provide valuable support for statisticians. *They must promote a culture which values good use of data and independent statistical input.*

The pandemic demonstrated the value of government data and statistics and the importance of the data literacy of senior leaders within governments. We found that senior non-analytical leaders within governments and organisations provided valuable support for statisticians, for example by championing the production and publication of new data. Senior leaders are also vital in developing an organisational culture that values evidence and analysis. This includes ensuring that statisticians are involved throughout policy-making and operational processes, and as performance measures are developed for new programmes. We found that some organisations developed a greater understanding of the need for official statistics and the importance of having embedded processes to produce statistics, for example at the Department of Health and Social Care, and Public Health England.

Our review of [Statistical leadership: Making analytical insight count](#) highlighted that senior non-analytical leaders need to know how and when to make the best use of statistical evidence. This includes knowing the right questions to ask analysts about data. The [Data Masterclass for Senior Leaders](#), developed by the Number 10 Data Science Team and now run by the Data Science Campus, is a positive step in building the skills and confidence of senior government leaders. It is good to see a commitment to developing data expertise in the UK Government's [Declaration on Government Reform](#).

Recommendation:

- Senior leaders and ministers within governments must be champions for trustworthy, high-quality, valuable analysis and must have the skills and knowledge to carry out this role.



Responsive and proactive

Lesson 3: The pandemic reinforced the need for statistics to inform society about public health and provide an understanding of how public health programmes are working. *Statistics producers should continue to develop outputs which go beyond operational data in order to support policy evaluation and a better understanding of public health.*

Official statistics on health and social care are often a by-product of the delivery of services. This means that they often focus on operational delivery, such as waiting times or hospital activity, rather than emerging population health issues and how they relate to other societal and economic issues. The pandemic demonstrated that good quality and timely data on operational delivery are essential. They helped governments and the public understand the ability of hospitals and care homes to cope with the increased pressures they were facing. It is also important that the public understand how government money is spent on delivering health services. But the pandemic showed that as a society we need to have a good understanding of population health issues – for example, in the case of the pandemic, to answer questions about the spread of coronavirus infections or the long-term impact of coronavirus infection on an individual’s health and wellbeing. It is important that producers continue to collect, publish, and develop information which goes beyond operational data and supports a broad understanding of public health. This may be as part of public health surveillance carried out by public health bodies, or as producers have done through the Office for National Statistics (ONS) [COVID-19 Infection Survey](#), or Public Health England’s analyses of [vaccine effectiveness](#). These data contribute to the evidence base required to understand public health, which includes academic research and other types of government analysis, such as social research.

The pandemic highlighted the importance of evaluating public health programmes. When we [reviewed NHS England Test and Trace statistics](#) in July 2020, we were clear that there were key questions which the publication was not able to answer, such as what proportion of people asked go on to complete self-isolation. We asked the UK Government to find ways to better understand the programme and its impact on the pandemic. We noted that this was unlikely to be answered solely through management information from the Test and Trace programme. We saw many significant improvements in Test and Trace statistics over the following year, as well as the publication of some information about the effectiveness of the programme [based on modelling](#). We welcome the Department of Health and Social Care’s [recent publication](#) on the impact of NHS Test and Trace on transmission. However, many important questions about the programme have remained unanswered – both as the UK went into the winter 2020 wave of the pandemic, and when we carried out a [second review of the statistics](#) prior to changes to self-isolation rules in England in August 2021. These include questions about the vaccination status of those who test positive, and how many close contacts identified through the tracing system go on to

test positive. In future, governments must ensure the early collection and publication of measures which allow public health programmes to be scrutinised and evaluated.

Recommendations:

- Governments must evaluate public health programmes and be transparent in sharing information about them with the public.
- ONS should consider how the COVID-19 Infection Survey can be adapted to play a role in understanding public health in future. This should be done in collaboration with other producers, including those in devolved administrations, and should consider the sustainability of representative population sampling.
- For the statistical system to be able to respond quickly to future health and social care issues, horizon scanning and sharing plans with each other should be focus areas for collaboration between producers. It is also important that analytical resource and data infrastructures are flexible enough to adapt to new demands.

Lesson 4: The pandemic exposed gaps in available data. *To ensure that statistics best serve the public good, these gaps must now be filled. Statistics producers should be proactive in meeting user needs to minimise gaps in future.*

The pandemic exposed and reinforced existing data gaps, for example in [social care](#), [ethnicity](#), and [mental health](#). This made it challenging for producers to meet user needs. For example, prior to the pandemic there was not a clear understanding of the number of people and the personal characteristics of people in care homes. As a result, in the early days of the pandemic, there was a lack of understanding about the impact of COVID-19 on people in care homes and initial data focused only on deaths in hospitals.

It is positive to see producers working hard to address these gaps. The recent development of [statistics for adult social care](#) in England now provide monthly information about vaccinations, infections, testing and availability of personal protective equipment in care homes. Collaboration between NHS Digital, ONS, NatCen Social Research and academics in England resulted in the large-scale [Mental Health of Children and Young People survey](#). This survey provides a unique insight into the mental health of children and young people during the pandemic. Our recent [review of statistics about children and young people](#) found that key statistics about COVID-19 have made this part of the population more visible. However, there are notable gaps in the information available, such as separate analyses for vulnerable children and data on social outcomes which give children themselves a voice. Overall, data gaps have often taken considerable time to address, not least because of the pressures of the pandemic which producers were working under, and in some cases gaps remain.

It is tragic that it has taken the pandemic to focus attention on issues such as [gaps in social care data](#). However, we are now encouraged to see greater attention to this issue from governments across the UK and strong commitments to making improvements. In Scotland, data on social care is a focus of the [Independent Review of Adult Social Care in Scotland](#) and 'The Future of Social Care and Support in Scotland' Parliamentary Inquiry. The Chief Statistician in Scotland also recently outlined the ambition to [improve the completeness of data on protected characteristics](#). In Wales, there is a focus on [improving the way social care data are used](#), and we are pleased to see a commitment to create an Equality Data Unit in the [Welsh Government's Programme for 2021 to 2026](#). There is also the [ongoing programme of work](#) by the Race Disparity Unit to improve the quality of ethnicity data on health records in England.

Recommendation:

- Producers must work with users to understand and address existing data gaps, such as those on social care, mental health, and ethnicity and other protected characteristics. The long-term and indirect impacts of the pandemic on society's health and wellbeing will also need to be understood.

Lesson 5: Data infrastructure impacted the ability of some statistics producers to respond to the demands of the pandemic. *Flexible and joined-up data infrastructures are needed so producers can respond quickly to new data needs.*

The speed of response of producers during the pandemic was highly impressive. As we highlighted in our [State of the UK Statistical System report](#) earlier this year, producers were quick to set up new data collections, data sharing processes and to publish new statistical releases. The sense that this was a contribution to a national effort, less bureaucracy, and a focus on 'good enough', rather than waiting for perfection, helped producers to be responsive and agile.

Where good data infrastructures were already in place, producers found it easier to adapt them and respond quickly. However, new operational systems created in response to the pandemic did not always consider future data and publishing needs – such as the issue of understanding the NHS Test and Trace programme in England discussed in lesson 3 above. We recognise that challenges with new operational systems will sometimes result in delays to publishing data. When this happens, producers should provide a clear explanation to users.

Existing challenges relating to data infrastructure also presented problems for producers – for example, fragmented data owned by multiple bodies, legal barriers, inconsistent formats, legacy software, and non-digital data. These issues resulted in challenges for data sharing and linking, and an over-reliance on burdensome manual processes – though we welcome the fact that some producers have since automated these processes. The [UK coronavirus dashboard](#) and the [NHS COVID-19 Data Store](#) are two examples of outputs produced using automated pipelines. We

encourage producers to build on these developments, automating processes using code where possible to reduce the risk of error and create processes which are sustainable and flexible – as recommended in our [report on Reproducible Analytical Pipelines](#). Producers should continue to consider what analytical code can be published or shared with other organisations to enhance transparency, reduce duplication of effort, and improve consistency – for all analysis, not just that relating to COVID-19.

We welcome the focus on improving technical infrastructure and data architecture in the [draft data strategy](#) for NHS England. The Department of Health and Social Care should ensure that those working on official statistics are included as key stakeholders in these efforts. Producers will also benefit from collaboration in this area – to learn from each other’s successes, such as the National Clinical Data Store in Scotland and the [National Data Resource](#) in Wales.

Recommendations:

- There is a need for improved, system-wide data infrastructures within each country. This will be challenging, but producers should learn from each other’s successes to make progress.
- Governments must involve statisticians and analysts when setting up new operational systems so that analytical requirements and publishing plans are built-in from the start, and so that there is a good understanding of the expectations of the Code of Practice for Statistics.

Lesson 6: Flexible use of analytical resource supported the impressive work by statistics producers. *Sufficient investments in recruitment and retention of skilled statisticians are required so statistics continue to be sustainable and responsive.*

The impressive response by producers required a large amount of resource and dedicated effort. Producers were quick to review existing work, deciding what could be paused to allow extra resource to be dedicated to the pandemic response. This included moving analytical staff between departments and organisations through a programme of loans and secondments, often supported by the [Analysis Function](#)’s analytical resourcing hub. Directors of Analysis played an important role in quickly redeploying staff to work on the pandemic response. However, in hindsight some producers reflected that this flexible sharing of resource could have been done more, and more quickly. The Analysis Function should consider the lessons from the approach taken during the pandemic and develop a model of resource-sharing which most effectively supports new demands in future.

Many producers feel that the past 18 months have been relentless, with staff working round the clock and through weekends and holidays – this level of work has continued for far longer than anticipated at the start of the pandemic. Maintaining

staff wellbeing and morale has been challenging. Many producers feel they are still responding to the pandemic while trying to reinstate previous work which was paused and meet new demands. A significant challenge for some producers is recruiting and retaining people with the right skills. In the past we have heard anecdotally that this was a challenge for the whole statistical system. The increased burden on producers during the pandemic appears to have exacerbated it further. However, relatively little is known or published about new starters, leavers and vacancies in the Government Statistical Service (GSS) – a data gap we highlighted in our [Statistical Leadership report](#) earlier this year. It is important to collect and share this information so that the scale of the problem can be assessed and effectively resolved.

Recommendations:

- To respond effectively to new priorities, analytical resource should continue to be shared flexibly across governments and non-government bodies. The Analysis Function should consider a longer-term resourcing approach across departments and professions, and also consider how the model used during the pandemic can be even more agile in future.
- Producers should continue to review their existing statistical releases. They should decide, based on balancing user needs with resource and the ongoing burden on staff, which statistics should be continued, restarted, or stopped, and how or with what frequency.
- The [GSS People Committee](#) should regularly monitor the membership of the Government Statistician Group, including information about central GSS recruitment and professional membership by organisation. The Analysis Function should regularly collate and publish data on the Analysis Function, including breakdowns by profession to better understand similarities and differences across analytical professions.



Lesson 7: Strong analytical collaboration resulted in valuable, high-quality, coherent statistics during the pandemic. *Taking this approach to other topics will help overcome existing and future problems.*

A shared vision and determination to support an issue of national importance resulted in impressive analytical collaboration during the pandemic. This included collaboration between producers – and collaboration with their data suppliers, policy and communication colleagues, other parts of governments, and with academic experts. For example, NHS boards and trusts played a pivotal role in providing data to central governments and public health bodies to inform the pandemic. It was also important to have strong working relationships with policy colleagues to understand rapid changes in policy and the impact of these on the data and statistics.

We saw that the amount of collaboration between producers increased and that the way they collaborated improved. Producers were more likely to reach out to each other when working on a new piece of analysis to ask for contributions or quality assurance. More-regular meetings on specific topics also helped to facilitate collaboration between producers. This approach should be applied to other health and social care issues and would have benefits more broadly across the statistical system. It is increasingly important that producers collaborate across organisations, particularly on issues which require data sharing and linking.

A challenge to collaboration in England is the number of different producers responsible for health and social care data – a result of the fragmented nature of the health and social care system overall. During the pandemic this sometimes resulted in duplication of work among producers or delays to figures being released – for example in the case of population estimates to understand vaccination rates. The number of producers publishing statistics about health and social care in England can also make it confusing for users to know where to find information. Since the role was introduced in April 2020, we have seen the value of having a Head of Profession for Statistics at the Department of Health and Social Care. This role has played an important part in coordinating outputs across organisations and providing support and guidance within the department and to arms-length-bodies. Given the issues that can arise from the fragmented nature of the system and the creation of a new body, the UK Health Security Agency, we consider that there should be clearer analytical leadership and coordination of health and social care statistics in England. Producers in England should come together to decide how this will work and Heads of Profession for Statistics have already begun work to address this.

We encourage producers in the four nations to continue to engage on projects to provide comparable data across the UK, as they have for vaccination statistics and the COVID-19 Infection Survey. However, we also recognise that differences in policies in each country may mean that providing UK-wide comparability is not always possible – in these cases collaboration between countries remains vital to

understand differences and their impact on the statistics. Producers should clearly explain to users any impact on the statistics and how they can be used, resulting from differences in policies across the UK.

We have previously highlighted the successes that result from formal collaboration with academics – for example, on the [COVID-19 Infection Survey](#), which contributed valuable expertise and helped develop new skills in the statistical teams in ONS. In Scotland, the [COVID-19 data and intelligence network](#) was established to foster collaboration between the Scottish Government, public bodies, and academics. The network allowed people to work together to solve challenges, such as data collection and data sharing. Similarly, the [One Wales approach](#) brought together partners from the Welsh Government, the NHS, academia and public health to share datasets and expertise. Collaboration between academics and several government departments and organisations also lead to the development of the [QCovid risk prediction model](#). The model was used to identify groups at high risk of being hospitalised or dying from coronavirus. This cross-organisational effort was awarded the [2021 Florence Nightingale healthcare data award](#) by the Royal Statistical Society.

Producers told us that a relatively new challenge for them was cross-government working outside the analytical community. The pandemic impacted every part of governments, not just the health and social care system. Therefore, producers also had to form new relationships with multiple government departments, to share data to inform policy decisions, manage operations and inform the public about the pandemic. Producers reflected that, looking beyond the pandemic, continuing to build broader relationships across governments will help improve collaboration in future.

Recommendations:

- There should be stronger analytical leadership and coordination of health and social care statistics. The need for this is most acute in England where the organisational landscape is most complex. Senior leaders should work together to decide how this will be implemented.
- To share best practice and tackle issues quickly and effectively, producers should maintain relationships built during the pandemic. Collaboration will be most beneficial when tackling shared goals, such as improving statistics on social care, mental health or ethnicity, and horizon scanning to anticipate future issues. Producers should proactively reach out to each other when working on a new topic or one which may be relevant to other producers or nations.
- Producers should continue to build relationships with other officials, including policy and communication colleagues, and other government analytical and scientific communities. This will mean that relationships exist to be in the best position for solving future problems.

Lesson 8: Sharing and linking data can have life-saving impacts. *This must be prioritised by governments beyond the pandemic.*

Data sharing and linking increased significantly during the pandemic. This allowed governments to develop policies and carry out rapid operational responses. The sharing of data between Public Health England, the Care Quality Commission and local authorities was vital for managing local outbreaks in care homes in England. Similarly, in Scotland the Care Inspectorate shared information about deaths, outbreaks, and staffing levels with the Scottish Government. This allowed vulnerable people in care homes to be identified. Linking data was also essential to develop clinically vulnerable patient lists in each country. The [Shielded Patient List](#) in England was used by health and care providers to support those who needed to stay at home, by other government departments to inform policies such as food parcels and statutory sick pay, and by mental health providers to support patients during and after shielding periods. In Wales, data linking was used to [analyse](#) the number of teachers and teaching assistants who were shielding, allowing the Welsh Government to understand the impact of the shielding policy on the provision of schooling during the pandemic.

In addition to being critical for the government response, data sharing and linking enabled analysis which enhanced the public's understanding of the pandemic and impacted personal decision-making. For example, [analysis by ONS](#) linking vaccination, census, general practice (GP) and hospital data provided insights on COVID-19 vaccine take-up. A better understanding of vaccination rates by socio-demographic characteristics contributed to a push in targeted campaigns, for example to [encourage vaccine take-up among ethnic minorities](#). We also heard that the pandemic has resulted in a better understanding across the NHS of the value of anonymised individual-level data and of providing high-quality data to be analysed centrally. Individual-level datasets provide a richer source of data than those at an aggregate level and are more flexible to adapt to new data needs. They also enable further value to be added by combining them with other data – for example, individual-level data for vaccinations and hospitalisations were linked to carry out analyses on the [vaccination status of those in hospital](#).

While examples like these clearly demonstrate the real-life impact of sharing and linking data, public consent cannot be taken for granted. This was illustrated by the recent backlash against the [sharing of GP data in England](#), which received largely negative media coverage¹. While the direct cause is not clear, during this time (between 1 June and 1 July 2021) [opt-outs increased](#) by about 1.2 million, from approximately 1.8 million to approximately 3 million. It is important that producers continue to demonstrate [trustworthiness](#), by being transparent about plans for data sharing and linking. Producers should engage in an open and meaningful discussion with the public about the risks and benefits of it. This will support public confidence in the sharing and linking of personal information in future.

¹ Examples of media coverage of plans for GP data sharing in England: [BBC news](#), [The Guardian](#), [The Financial Times](#), [The Daily Express](#)

Data sharing and linking has historically been hard to achieve. Producers reflected that barriers include technical infrastructure, a tendency to be highly risk-averse and a cultural mindset where the default is not to share. A particular challenge raised by some devolved administrations and arms-length-bodies is ensuring that data sharing is two-way between themselves and central government. Some of these barriers remain, such as challenges with infrastructure. However, government data sharing notices and a clear need to share data to support the pandemic response helped to overcome many of them.

We welcome the commitments to improving data sharing and linking in the [draft data strategy](#) for NHS England and the UK Government's [Declaration on Government Reform](#). For this to be successful, it is important that governments sufficiently prioritise and resource work on data sharing and linking. We will continue to push for data sharing and linking, building on our [previous work on joining up data](#).

Recommendations:

- Governments must prioritise data sharing and linking. This should include sufficient investment, and support through legislation where necessary.
- Organisations must embed a culture of data sharing. This will be challenging, but will be supported by developing understanding of current barriers. Addressing our previous recommendations on collaboration and system-wide data infrastructures will also help to support more data sharing and linking in future.
- Producers must be transparent and engage with the public about plans for data sharing and linking. Publicly sharing positive stories about the real-life impacts of safe and secure data sharing and linking will help with this.



Clear and insightful

Lesson 9: When data and statistics are clearly presented, they are valued by the public. *Statistics producers should apply the lessons they have learned about how to improve public communication to other statistics.*

The pandemic raised the public profile of data, statistics, and statisticians. Producers felt valued and relevant, helping them to deliver under immense pressure. The level of public interest in data and statistics about the pandemic is likely to be an extreme example. Nevertheless, it is good that producers plan to apply lessons learned about how to improve public communication to other statistics. These lessons include the success of dashboards to meet varied user needs and the benefits of multidisciplinary teams – for example, involving subject experts, statisticians, and data visualisers. Having data, or links to data, in one place was also beneficial for users, for example [in Scotland](#). While it is not essential to have all data on a topic accessible in one place, it is important to sign-post users to related information. We have seen ONS provide this broad picture well in its [coronavirus roundups](#). Given the many different producers in England, part of a coordination role which we have recommended in lesson 7 above should consider how best to help users find all the data they need.

The pandemic highlighted the importance of statisticians meeting the needs of users from the media and supporting them as intermediaries with the public. Technical briefings between statisticians and the media in Scotland, Wales and Northern Ireland resulted in improved reporting – we highlighted the [briefings in Northern Ireland](#) in our State of the UK Statistical System report. At Public Health Scotland, support from the communications team was particularly important in building good relationships between the organisation and journalists. It has been positive to see statisticians directly engage more with the media – in these ways, and through more-regular appearances on radio and television. [We would like to see senior leaders give statisticians across all organisations the opportunity to do this more.](#)

Statistics and data should be presented clearly and explained meaningfully to users. A challenge in communicating data and statistics about COVID-19 was that producers were having to continually learn what information was needed and how to best measure it. There was often no established method and sometimes agreeing definitions between producers and countries was challenging. Meeting varied user needs sometimes resulted in different published measures, for example on [COVID-19 deaths](#) or [vaccination denominators](#). While, in these cases, each measure had value to meet a different purpose, this was not always clear to users. In future, producers should communicate clearly when users should use different measures, what the strengths and limitations of these are, and why differences exist.

Recommendation:

- Producers should reflect on the lessons learned about the communication of statistics during the pandemic and apply these to their other work – for example, how to best communicate with the public and the media. Producers should share these lessons with each other and the wider statistical system.



Timely

Lesson 10: The pandemic highlighted the value of timely health and social care statistics. *However, there is always a balance between timeliness, quality and resource, and producers must be transparent about this with users.*

The response of producers to publish close to real-time data was remarkable – for example, daily updates on COVID-19 cases and deaths. Producers demonstrated the ability to consider user needs when balancing timeliness against quality – for example, quickly moving to daily vaccination data at the start of 2021 as public interest in the success of the vaccination programme intensified. However, it is also important that producers consider the resource implications of producing such frequent data. We discussed in lesson 6 the increased pressures on staff that have resulted from the pandemic. As society comes out of the pandemic, we are supportive of producers reviewing the frequency of their COVID-19 statistics in terms of how useful and meaningful this is for users. In some cases, this process may lead to rationalising outputs which are no longer as relevant, and in others it may involve further developing or regularising releases which have so far been ad-hoc.

Recommendation:

- Producers should consider the trade-offs between timeliness and accuracy of statistics and clearly explain decisions taken on these to users.

Next steps

We have made several recommendations designed to support governments and statistics producers to build on the lessons learned during the pandemic to improve health and social care statistics in future. These recommendations will need to be taken forward by statistics producers and senior leaders within organisations and governments. We recognise that many producers still face considerable pressures due to the ongoing pandemic response. We expect that producers will act on these recommendations as society comes out of the pandemic. We also expect that these recommendations will support more-immediate improvements, for example as part of new government strategies and newly formed organisations.

We will continue to work closely with users and producers, and will engage where relevant more broadly across governments, to push for progress on these recommendations. This will be complemented by follow-ups of our report on [joining up data](#) and our reviews of [adult social care](#). We will also focus on transparency and improving government processes for releasing data in our engagements and regulatory work. We plan to provide an update to this review in autumn 2022 setting out progress to date.

If you have feedback or would like to discuss any aspect of this report, please contact us via regulation@statistics.gov.uk.