Office for Statistics Regulation

2022 update: lessons learned for health and social care statistics from the COVID-19 pandemic

October 2022

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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.

In brief

The COVID-19 pandemic reinforced the vital role that data and statistics play in our society and their ability to serve the public good. In our 2021 review of lessons learned during the pandemic we commended the remarkable response by producers of health and social care statistics to meet the increased public demand for data and statistics. This year (October 2021-October 2022) we have undertaken a follow-up to our 2021 review. Much like the UK's health services, we have found a statistical system which is transitioning from pandemic crisis mode to living with COVID-19. The main challenge of this transition is sustainability. It has been possible to meet the increased analytical demands of the pandemic thanks to the extraordinary, dedicated efforts of producers. However, it is unclear how sustainable it will be for producers to maintain current levels of work.

In the context of the increased demands on producers, we identified four areas which support the production of statistics which serve the public good. Firstly, producers must horizon scan to understand what information people need and therefore prioritise effectively. We found good alignment between producers and users on which topics they consider to be of highest importance. These include statistics on waiting times, the indirect impact of the pandemic on services, social care and health inequalities. It will be important that producers continue to engage with each other and their users to ensure the ongoing alignment of priorities.

Once producers have a good understanding of user needs, they must ensure that data and statistics are made available in an accessible, transparent and timely way. While we have continued to intervene over the last year where lack of transparency is an issue, we have found that producers are quick to respond. There is a better understanding of the need for intelligent transparency and producers are becoming champions for it within their organisations. We are also encouraged by the ongoing efforts by producers to address existing data gaps, including on social care, mental health and ethnicity.

In order to publish statistics which provide maximum value for users, producers will often need to collaborate to share data and improve coherence. We found that topic-based groups have supported effective collaboration between producers and helped to increase the coherence and comparability of statistics for users. Although we identified more good examples of collaboration to share data, many of the same barriers we highlighted last year remain, including a lack of clear, consistent guidance on managing legal and information governance issues.

Finally, producers must continue to innovate to communicate their statistics in a clear and engaging way to a wide range of users. We found that producers have a greater appreciation for the need to communicate with, and meet the needs of, a range of different users. As a result, producers have learned that there may be a need to publish a variety of products and have made good use of different mediums for communicating their statistics, including dashboards and social media. We have identified a need for further guidance on the use of dashboards and Twitter to support producers to add value for users. We also identified a risk to health and social care statistics serving the public good if they are misused. We want to see producers being proactive to minimise this risk in future.

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Introduction

It has been nearly three years since the start of the coronavirus pandemic. The impact of COVID-19 on individuals and society has been profound. In the UK, to date, there have been over 200,000 deaths involving COVID-19. The UK implemented unprecedented lockdown rules in order to slow the spread of the virus, restricting the reasons for which people could leave their homes. And, as the UK moves to a new phase of the pandemic, its health and social care services face immense pressures. The latest figures show that, in England, ambulance response times have increased, over seven million people are waiting for planned hospital treatment (the highest figure since records began), and 38% of patients missed the two-month waiting time target for cancer treatment following an urgent GP referral. Similar pressures on services are being experienced in Scotland, Wales and Northern Ireland. There is rightly a desire to learn lessons from the pandemic, with public inquiries underway to understand the UK's response and the response in Scotland.

The impact of COVID-19 on health and social care statistics

In the UK, the statistical system comprises the community of producers who publish official statistics, as well as those involved in the wider ecosystem of statistics and data used to explain and understand life in the UK. This includes epidemiological analyses and published management information.

The need to understand and manage the pandemic placed huge demands on the UK's statistical system. The impact of the pandemic was most acute for health and social care statistics, which cover public health and health and social care services.

This year (October 2021-October 2022) we have undertaken a follow-up to our 2021 review of the impact of the pandemic on health and social care statistics. Last year we commended the remarkable response of health and social care statistics producers to meet the huge public appetite for data and statistics about COVID-19. We found that producers worked quickly and collaboratively to inform and engage the public, in many cases overcoming challenges which would previously have seemed insurmountable. However, the pandemic also drew attention to existing problems and created new challenges for health and social care statistics. There were gaps in important information and it was not always clear where users could find the information they needed or which data they should use.

Timeline of the pandemic

March 2020	11th: WHO declares COVID-19 a pandemic
	23rd: Prime Minister announces first UK lockdown, requiring people to 'stay at home'
April 2020	1st: Launch of Public Health Scotland
	2nd: The UK Government announces its strategy for increasing testing across the UK, including an ambition to conduct 100,000 tests per day by the end of April
May 2020	28th: Launch of the NHS Test and Trace programme in England
December 2020	8th: The UK's vaccination programme begins
	18th: Public Health England designates the Alpha variant as a new 'variant of concern'
May 2021	7th: Public Health England identifies the Delta variant as a new 'variant of concern'
October 2021	1st: Launch of UK Health Security Agency and creation of the Office for Health Improvement and Disparities within the Department for Health and Social Care in England
November 2021	21st: UK Health Security Agency identifies the Omicron variant as a new 'variant of concern'
	30th: UK government announces that all adults in England over the age of 18 will receive a booster vaccine by the end of January 2022
April 2022	1st: Implementation of the UK Government's Living with COVID-19 plan, including the end of free mass testing in England

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| May 2022 | 25th: Scottish COVID-19 inquiry formally opens |
| July 2022 | 21st: UK COVID-19 inquiry formally opens |

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Main findings and recommendations

The situation in 2022

The pandemic reinforced the vital role that data and statistics play in our society and their ability to serve the public good. Data and statistics enhanced public understanding on important issues and supported individuals to reach informed decisions and hold their governments to account. In the context of the increased demands on producers, we have identified four key areas which support the production of statistics which serve the public good.

- Firstly, producers must understand what information people need so that they can prioritise effectively. This involves engaging with users to understand their needs and developing a good understanding of issues which are topical or likely to become topical in the near future; horizon scanning in other words.

- Once producers have a good understanding of user needs and issues of high public interest, they must ensure that data and statistics are made available in an accessible, transparent and timely way.

- In order to publish statistics which provide maximum value for users, producers will often need to collaborate to share data and improve coherence.

- Finally, producers must continue to innovate to communicate their data and statistics in a clear and engaging way to a wide range of users.

Each of these areas is explored in more detail later in this report.

Over the last year (October 2021-October 2022), we found excellent examples across health and social care statistics in each of these four areas (horizon scanning, making data available, collaboration and communication). Collaboration and communication are two areas which were particularly successful during the pandemic. Sharing good practice and lessons learned from these achievements will be helpful for the whole of the UK's statistical system.

Sustaining innovations to health and social care statistics

Much like the UK's health services, we have found a statistical system which is transitioning from pandemic crisis mode to living with COVID-19. The main challenge of this transition is sustainability – by which we mean the ability of health and social care statistics producers (referred to as producers from now on) to sustain current levels of work. It has been possible to meet the increased analytical demands of the pandemic for the past two and a half years, thanks to the extraordinary, dedicated efforts of producers. However, it is unclear how sustainable it will be for producers to maintain current levels of work, particularly as new priorities emerge and while the challenges of recruitment and retention of staff, which we highlighted last year, remain.

While the intense demands of the pandemic have now eased for producers, a real challenge is maintaining some level of analysis relating to COVID-19 while working on other priorities. Ongoing demands include the production and publication of

statistics about COVID-19, publishing new statistics to measure emerging issues, such as new disease outbreaks, and re-invigorating 'business as usual' statistics, such as those on NHS performance and workforce. Some of these increased demands can be seen in the increase in analytical outputs throughout the pandemic – for example, Public Health Scotland told us that it experienced a roughly one third increase in publications since the beginning of the pandemic. Many health and social care producers are also responsible for producing internal analyses for the management of services and direct care purposes, such as identifying and managing patient cohorts.

In the UK, the pandemic is in a different stage now than it was during the first 12 to 18 months: vaccines and treatments have dramatically reduced the risk of severe illness and death from COVID-19 for most people. As a result, governments across the UK are managing the pandemic in a different way, for example through the UK Government's Living With COVID-19 policy which eased the majority of domestic restrictions in England. The consequent decline in public and media interest in COVID-19 statistics has helped to ease the burden for producers. However, many have found it hard to reduce or remove outputs about COVID-19 due to some level of continuing user demand, even if the value of the information is no longer as high. Producers have also found that there is a growing expectation that non-COVID publications should be produced at a similar pace and scale as statistics about the pandemic.

In these circumstances making the best use of analytical resources is essential. Producers are managing demands through prioritisation and by working differently (for example, by automating manual processes and increasing the use of dashboards, which can be less resource intensive in the long-term though do require upfront investment to development). As we have said before, we are supportive of producers reviewing their existing statistics to decide which should be continued, restarted, or stopped, and how or with what frequency. This should be based on balancing user needs with resource and the ongoing burden on staff. It should be noted that engaging with users to understand their needs and agree changes to statistics also requires dedicated resource. However, we consider that this engagement is essential to ensure that statistics provide value and to support producers to prioritise appropriately.

Next steps

There is still progress to be made against several recommendations in our 2021 report, including on the transparency of numbers used publicly by governments and on overcoming barriers to data sharing. We have also identified some new areas which require focus. We want to see producers being proactive to minimise the misuse of their statistics. And there is a need for further guidance from the Analytical Function Central Team on the use of dashboards and Twitter to communicate statistics to a broad range of people.

We continue to work closely with users and producers of health and social care statistics, and will engage, where relevant, more broadly across governments, to push for progress on our recommendations. We will advocate for and support solutions to improve transparency through our ongoing intelligent transparency

campaign. Our planned review on data sharing and linking will gather examples of good practice as well as develop our understanding of barriers to support positive change. We also continue to monitor issues relating to transparency and the misuse of statistics through our casework.

The following sections of this report expand on the four key areas that support the production of statistics that serve the public good (horizon scanning, making data and statistics available, collaboration and communication).

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

Horizon scanning: looking to the future of health and social care data and statistics

What we said in October 2021:

- Statistics producers should be proactive in meeting user needs to minimise gaps in future.

What we found during October 2021-October 2022:

In order to ensure that statistics provide the information people need, producers must have a good understanding of their users. They must also be aware of issues which are topical or likely to become topical in the near future. We asked both users and producers of health and social care statistics which topics they think will be of highest importance over the next few years. It is encouraging that the answers given by producers and users align very closely. The topics mentioned most frequently by both groups were: waiting times and NHS performance more generally; the indirect impact of the pandemic on services; social care; and health inequalities. Other topics raised by both groups included workforce, mental health, respiratory surveillance, primary care and, in Scotland, drug deaths. We found that, as a result of the increased public engagement in data and statistics about COVID-19, many health and social care producers have developed their understanding of their users – who they are and what they need. This is discussed in more detail in the section on Communication: engaging a wide range of audiences and minimising misuse . It will be important that producers continue to engage with users to ensure the ongoing alignment of priorities. It will also be useful for producers to continue to engage with each other to share insights and identify priorities. For example, the English health statistics leadership forum carries out collaborative horizon scanning among producers in England in order to anticipate future statistical needs.

There are several developments relating to health and social care data across the UK which we consider will support producers in their ability to provide information on these important topics in future. For example, the Data Saves Lives strategy for

England supports the use of health and social care data for official statistics and is ambitious about improvements for both health and social care data. The Scottish Government is currently developing its [Data Strategy for health and social care](#). Given that the pandemic demonstrated the importance of providing aggregated statistics to inform a wide range of people, we hope to see this purpose of health and social care data included in the final strategy. In Northern Ireland, the development of a new digital integrated patient record across health and social care through the [encompass programme](#) provides an opportunity to improve currently disparate IT systems and allow greater standardisation of data. Robust data collection methods are the foundations on which good statistics are built, so this is a huge step forward towards improving statistics on health in Northern Ireland. In Wales, the ongoing [transformation of health and social care using digital and data services](#) presents several opportunities to improve the development and effectiveness of statistics, including the development of the [National Data Resource](#) and a [strategic approach to social care data](#). The successful implementation of all of these data strategies and projects will depend on sufficient resource being made available, for example to turn new operational data into published statistics.

Making statistics available: enhancing understanding of topics of high public interest

What we said in October 2021:

- 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.

- The pandemic exposed gaps in available data. To ensure that statistics best serve the public good, these gaps must now be filled.

What we found during October 2021-October 2022:

One of the main ways in which statistics can serve the public good is for them to help people to understand the world around them, providing the information they need about the issues they care about. In order for this to happen, statistics need to be available at the right time and be shared in a transparent way. A lack of transparency and data gaps can both impact the ability of statistics to enhance public understanding on important topics.

Intelligent transparency

Last year, in response to recurring issues with transparency identified through our [casework](#), we launched our [campaign for intelligent transparency in statistics and data](#). Throughout this year (October 2021-October 2022*)* we have continued to intervene both publicly and privately through our [casework](#) where lack of transparency is an issue – for example, on the use of unpublished statistics about the [cost of the UK's Test and Trace programme](#), [vaccination status of COVID-19 patients in critical care beds in Wales](#) and [COVID-19 hospital admissions for children](#)

in Scotland. It is important to note that in these cases, producers were quick to recognise and respond to the problem. We have found that there is a better understanding of the need for intelligent transparency and that producers are being champions for it within their organisations. Producers now have good processes in place for the quick release of analyses, often as a result of the demand for this during the pandemic. We have also had feedback that our regulatory guidance on transparency, published in February 2022, has supported producers in their efforts to achieve intelligent transparency. We recently published a blog and answers to Frequently Asked Questions to support others to advocate for intelligent transparency across government data, statistics and wider analysis.

There are many good examples of new health and social care data being published over the last year, supporting transparency on topics of high public interest. For example, there have been new publications on antiviral drugs for vulnerable people in Wales, bed availability in England and the ambulance service in Scotland. Our rapid review of the Scottish Ambulance Service (SAS) statistics published in June 2022 highlighted that "*These statistics were first published in November 2021 in response to high public interest on the topic... By publishing these statistics SAS is supporting transparency, enabling individuals and organisations to reach informed decisions and answer important questions*".

Intelligent transparency is about supporting an open and accessible approach to communicating numbers. It is achieved by following three core principles:

- **equality of access** (data and statistics quoted publicly are made available to all)

- **enhancing understanding** (data and statistics enhance understanding of societal and economic issues)

- **analytical leadership** (decisions about the publication of statistics and data are independent of political processes)

These principles are applicable to official statistics, as well as other types of analysis such as research, management information and evaluations.

The pandemic exemplified why intelligent transparency is so important. There was a huge public demand for data and statistics about COVID-19 – probably best seen in the over 1 million users per day experienced during peak times by the UK Health Security Agency's COVID-19 dashboard (created in 2020 by Public Health England). The statistical system's response to meet the increased demand for information was impressive – there were lots of examples of publishing data and analysis of high public interest in an open and insightful way, including the UK dashboard and similar dashboards published in all four nations of the UK. The UK dashboard was the 2022 winner of our Award for Statistical Excellence in Trustworthiness, Quality and Value, awarded in partnership with the Royal Statistical Society and Civil Service World.

The benefits of intelligent transparency are clear. Firstly, it builds trust in the organisations which produce data and statistics. While it focuses on the Office for National Statistics (ONS), rather than the whole statistical system, the 2021 study by NatCen provides an indication of public trust in producers of official statistics, with

79% of respondents agreeing that COVID-19 statistics are accurate and 87% of respondents trusting ONS statistics. The main reason people gave for trusting ONS was that ONS did not have a vested interest in the results – this independence is at the heart of analytical leadership, one of the three core principles of intelligent transparency.

Secondly, transparency ensures that public conversations focus on the important issues. During the pandemic we found that a lack of transparency often resulted in confusion about where numbers came from or accusations that governments cherry pick or manipulate data. We saw examples of these kind of issues in the media and on social media, as well as through our casework, for example on testing numbers and modelling during the Omicron wave (see the case study below).

Finally, making data available also allows independent analysis to be carried out by others, enhancing its value. For example, the UK COVID-19 dashboard allows users to easily download the data or to access it via an API (application programming interface) in order to carry out their own analysis. During the pandemic this resulted in excellent visualisations and additional insights being created from the data by people outside of the statistical system – we blogged about some of our favourite examples in August 2022. And there have been many other examples of the value of making data available for reuse, such as the Travelling Tabby Scotland Coronavirus Tracker. The site was created and run by John Frace, a student at Argyll College, and was commended by Professor Linda Bauld, Professor of Public Health at the University of Edinburgh, who said of the site's creator: "*With his website he has provided easily accessible analysis and visualisation of coronavirus statistics from Scotland and the UK, alongside local data and international comparisons*".

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Case study: Supporting public understanding of the number of Omicron infections

On 13 December 2021, the Secretary of State for Health and Social Care delivered a statement to parliament saying that "*The UK Health Security Agency estimates that the current number of daily infections are around 200,000*". At this time, the UK COVID-19 dashboard showed that the number of cases was around 45,000. The public were familiar with these figures, which were regularly covered by the media and used in press briefings, and so were confused when they heard the 200,000 figure – had cases suddenly jumped four-fold? Where did this new figure come from and what did it mean? The answer was that the two figures measured different things. The 200,000 figure was a modelled estimate of the number of Omicron infections in the population. This included people who had just been infected but didn't know that yet. The number presented in the dashboard was the number of positive cases reported through the testing programme. But, based solely on the statement, it was hard for people to know this.

In response to this confusion, UKHSA worked quickly to publish an explainer about the 200,000 figure on 16 December. This included detail about underlying assumptions, data sources and limitations of the calculation. UKHSA also quickly published a daily overview of Omicron cases, hospitalisations and deaths, starting on 14 December. On 17 December we wrote to UKHSA, a relatively new organisation established in October 2021, welcoming the publication of data to support the statement made by the Secretary of State. We acknowledged the commitment UKHSA had shown to share data to support public understanding in such a fast-moving environment.

UKHSA reflected afterwards that issues like this can distract from the key public health message and issues, and can risk delaying buy-in from the public if trust is undermined. UKHSA also identified that ad-hoc releases can be a useful way to provide short explanations to support figures used by ministers. UKHSA now has processes in place for rapidly producing ad-hoc releases, both for proactive and reactive releases.

Data gaps

The ability to inform the public on issues which matter to them can be hampered by the absence of statistics and data, as well as issues with transparency. Our 2021 report highlighted critical data gaps exposed by the pandemic in social care, mental health and on protected characteristics, particularly ethnicity. Users continue to raise these data gaps with us, as well as gaps in other areas such as independent healthcare and healthcare spending. We have also used our voice over the last year to raise the ongoing issue of data gaps – for example, discussing gaps in social care, primary care and ethnicity data in an evidence session with the Scottish Parliament's COVID-19 Recovery Committee in May 2022.

We are encouraged to see ongoing efforts to fill many of these gaps by producers across the UK. For example, on social care, individual level data is now being collected in England from early adopters in the adult social care sector. NHS Digital is working towards mandating this dataset as of April 2023 and aims to use this as the source of official statistics in future. In Wales, a new data collection is planned in which each social care provider will be required to submit an annual return. This requirement is set out in legislation under the Regulation and Inspection of Social Care (Wales) Act 2016, with both the Act and The Regulated Services (Annual Returns) (Wales) Regulations 2017 specifying the information which must be collected. While the pandemic delayed the rollout of returns, these will commence from April 2023 and will provide insight into staffing, the number of people supported, charges and accommodation facilities. The Act also requires the publication of annual returns and these data will also be made publicly available at an individual service level. Finally, the Scottish Government is working with Public Health Scotland and other partners to carry out a review of nationally collected care home data during 2022/23. The aims of the review are to ensure a coherent suite of data collections, reduce the burden on data providers and meet the existing and emerging needs of data users. A key element of the project will be identifying data issues and gaps, including in relation to equalities data, to inform how best to collect this information. The care home data review forms one strand of a wider review of the entire social care data landscape in Scotland, in light of the Scottish Government's policies on health and social care integration and the establishment of a National Care Service.

On mental health, NHS Digital has started to publish an interactive dashboard which presents time series data from the Mental Health Services Monthly Statistics publication. This dashboard was developed using a user centred design approach meaning that views were gathered from a range of sources including submitters of data, charities, media and journalists, as well as policy leads. Alongside the dashboard development, NHS Digital has developed its demographic reporting for mental health statistics, including the reporting of some characteristics for the first time, such as gender, age, ethnicity and deprivation. Whilst other newly published breakdowns, such as accommodation status, employment status, disability and sexual orientation, do not have high data quality at present, NHS Digital hopes to work with providers to improve data quality in future. In Northern Ireland, following our review of mental health statistics, the Mental Health Outcomes Framework Group has made progress in identifying the data needed to support Outcomes Based Accountability reporting on mental health services. The Framework Group will make recommendations on how data should be gathered at source, particularly for the community sector, and is likely to recommend that the changes needed to collect robust and consistent activity data should be taken forward alongside the roll-out of a new administrative system in Northern Ireland. In the shorter-term, the Department of Health in Northern Ireland is focussing on Child and Adolescent Mental Health data, with the aim of publishing statistics about this service.

On ethnicity, during the pandemic NHS Digital created an ethnic category information asset to provide a near population level view of ethnicity in England for COVID-19 planning and research. This approach combines data from general practice and hospital episode statistics to provide 94.8% coverage for the most recent data collected. NHS Digital also includes breakdowns by ethnic group in its

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publications on [maternity services](#) and [activity](#), adults receiving [long-term social care support](#) and on the [use of Psychological Therapies](#) for treating people with depression or anxiety. Similar breakdowns by ethnic group are available in the [excess mortality reports](#) published by the Office for Health Improvement and Disparities. As noted in the section on Horizon scanning: looking to the future of health and social care data and statistics, once new operational data streams are underway, new data should become available to enable producers to publish statistics which continue to close existing data gaps.

Collaboration: working together to maximise value for users of data and statistics

What we said in October 2021:

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

- 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.

- We encourage producers in the four nations to continue to engage on projects to provide comparable data across the UK. However, we also recognise that differences in policies in each country may mean that providing UK-wide comparability is not always possible. 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.

What we found during October 2021-October 2022:

Strong collaboration was an essential part of the statistical system's response to the pandemic. It demonstrated that through collaboration, producers can better meet the needs of users. We found two main purposes for collaboration during our follow-up: working together to share data and working together to produce coherent, and where possible comparable, statistics.

Collaborating to share data

On data sharing, our overall finding remains the same as in [our 2021 report](#): while data sharing increased during the pandemic, barriers still exist. Over the last year (October 2021-October 2022), there have been more good examples of sharing data between producers in order to produce new statistics (see the case study below). We also found that data sharing initiatives established during the pandemic have resulted in producers gaining a greater appreciation of the benefits of sharing data with each other, such as improving data quality. Producers are therefore more likely

to explore new data sharing projects. However, producers identified many of the same barriers we highlighted last year, including a lack of clear, consistent guidance on how to manage legal and information governance issues, and a reluctance among some to share data. These issues are broader than just health and social care data – they are relevant for the whole statistical system, as we set out in our 2022 State of the Statistical System report. Data sharing will be an area of focus for us over the next year as we follow up our Joining Up Data reports.

The Goldacre review, published in April 2022, is a key development in this area from the last year. The review explored ways to deliver better, broader, safer use of NHS data for analysis and research in England. The recommendations from the review include building a small number of secure analytics platforms (often referred to as Trusted Research Environments or TREs) and making these the norm for all analysis of NHS patient data, including by academics and NHS analysts. The use of TREs was endorsed by users we spoke to and was also strongly supported by the citizens' juries on health data sharing in a pandemic jointly commissioned by the National Data Guardian for Health and Social Care, NHSX and the National Institute for Health and Care Research Applied Research Collaboration Greater Manchester. There are already some TREs across the UK which provide access to health data for research, such as the NHS Safe Havens in Scotland and the SAIL Databank in Wales. We hope to see further developments in this area to support safe health data sharing within and beyond the government analytical community.

Case study: Sharing data to produce statistics on self-funded adult social care in England

In 2020, the Office for Statistics Regulation published a report on Adult Social Care statistics in England. Our review identified a data gap regarding privately funded provision of adult social care. This made it difficult to estimate the size and spending of the self-funding population.

Through engagement with the Department of Health and Social Care (DHSC), statisticians at the Office for National Statistics (ONS) became aware of new information which the Care Quality Commission (CQC) had started to collect in 2019 within the Provider Information Returns (PIR) on funding of service users. Working together, the CQC and ONS put in place data sharing agreements to provide ONS with access to the PIR data in order to produce estimates which inform DHSC's funding allocation. Since the PIR data are collected under Regulation 17(3) of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, an extract of data relating to the people who use the service can be shared under Article 6(1)(c) and (e) and Article 9(2)(h) and (i) of the General Data Protection Regulation (GDPR). This is specified in the CQC Adult Social Care PIR guidance.

ONS links the PIR data to the National Statistics Postcode Lookup, which relates postcodes of care homes to a range of geographies, and to the CQC's Care directory, which provides information about the characteristics of individual care homes.

CQC makes the relevant data available to ONS via its secure online platform. ONS then shares its analysis with CQC and DHSC prior to release for quality assurance purposes. One of the early challenges for ONS in analysing these data was understanding the dataset to determine which variables would be used for weighting. To overcome this, ONS had multiple discussions with CQC and DHSC about the best variables to use as both are experts in the data. ONS is also working with CQC to explore how the quality of the PIR data can be further improved.

As a result of this collaboration, ONS now publishes annual statistics on the estimated population of self-funding care home residents.

Collaborating to produce coherent statistics

Our 2021 report identified the need for stronger analytical leadership and coordination of health and social care statistics. The most acute need for this was in England, where the organisational landscape is the most complex. In response to our recommendation, the English health statistics leadership forum was established, bringing together Heads of Profession for Statistics and lead statisticians from across the health statistics system in England. The forum aims to ensure that statistical

outputs are aligned and complement one another, as well as taking a joined-up approach to prioritisation, horizon scanning and methodologies. Recently, an equivalent four nations leadership group has also been established, to complement other topic-based four nation working groups.

We found that topic-based working groups have been particularly successful in supporting a coordinated approach to health and social care statistics. During the pandemic, cross-UK groups were an essential part of the delivery of UK-wide statistics about COVID-19 deaths and vaccinations, as well as the UK COVID-19 dashboard. The cross-UK group on social care resulted in the creation of the UK adult social care statistics landscape page, which brings together statistics on social care for the whole of the UK. This includes a four nations matrix which informs users about which data are and are not comparable across the UK. In Scotland, the COVID-19 Data and Intelligence Forum was a successful way for producers to collaborate during the pandemic. This approach is now being used for social care data and statistics with the establishment of a Social Care Data and Intelligence Forum. The Forum oversees a joint work plan for Public Heath Scotland and the Scottish Government, aiming to improve cross-organisational coordination, data sharing and information governance.

As well as increasing coherence and comparability of statistics for users, these collaborations have benefited producers. Producers told us that they have more awareness of what other organisations are doing, know who to contact in order to collaborate and have improved joint horizon scanning. Producers want to continue this level of collaboration, expanding some of the four nations groups which are currently focused on COVID-19 to include other topics (for example, the vaccine group expanding from COVID-19 to include flu and other vaccines). The English Health Statistics Steering Group (EHSSG) has played a key role in supporting several of these topic-based groups. The EHSSG was established in 2016 with the aim of enhancing the coherence, production, dissemination and accessibility of health and care statistics in England. In its 2022-2027 workplan, the EHSSG states the importance of UK level coherence and where possible aspires to achieve this. We support further use and development of topic-based working groups in order to continue to improve statistics for users – for example, the cross-UK group on performance statistics, which includes waiting times, will be an important group coming out of the pandemic given this is a priority topic for users.

Users of health and social care statistics often need to compare statistics, for example between geographical areas. We found that users of health and social care statistics, such as parliamentary researchers and health think tanks, have a strong interest in comparable UK-wide data. Topics which users said they wanted comparable UK information on included waiting times and spending. Users do appreciate that comparability is not always possible due to differences in policies and operations in the four nations.

However, users told us that it can still be hard to determine exactly what is and is not comparable across the UK. For example, it is good to see that the EHSSG and statisticians across the UK have done a lot of work to understand and summarise differences in waiting time statistics. But this information, or a link to it, is not included in all of the relevant publications for each nation to easily inform users about comparability.

Some other examples users gave us where a lack of comparable data presents a challenge include inconsistent groups (e.g., different age bands used across organisations) and inconsistent measures and presentations of statistics. For example, we heard from researchers at the Nuffield Trust about the challenges they faced using statistics about deaths. In putting together comparable data on the location of deaths across the UK (see Annex 4 of the Nuffield Trust's Support at the end of life report), the researchers found that obtaining sources with comparable time periods and definitions, and containing data on actual and 5-year averages, was difficult.

There remains more work to do to improve cross-UK comparability of statistics. We encourage producers in the four nations to continue to collaborate to publish comparable data where possible. This includes considering methodologies and definitions used, as well as the presentation of the statistics. Where UK-wide comparability is not possible, producers should clearly notify users that this is the case to aid user understanding and support appropriate use.

Communication: engaging a wide range of audiences and minimising misuse

What we said in October 2021:

- 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.

What we found during October 2021-October 2022:

Meeting the needs of a varied range of users using different mediums

The final stage in ensuring that health and social care statistics serve the public good is good communication. We found that, as a result of the increased public appetite for data and statistics about COVID-19, producers have a greater appreciation for the need to communicate with, and meet the needs of, a range of different users. This includes members of the public who are accessing statistics for general interest, to make decisions about their lives or to enhance their understanding of an issue of high public interest. This was often a big change for producers, many of whom were used to communicating with other audiences (usually other parts of government or experts, such as academics). As a result of developing this understanding of the varied users of statistics, some producers have identified that one product does not necessarily suit all. Three themes emerged from our evidence, focussed on three different mediums for communicating statistics: dashboards, reports, and social media, specifically Twitter.

Dashboards

It is clear that dashboards were a hugely popular way of communicating statistics to the public during the pandemic. We have already discussed the astonishing number of hits that the UK COVID-19 dashboard experienced during peak times. There were also extraordinary levels of engagement with dashboards produced in other UK nations – Public Health Scotland's COVID-19 dashboard received over 120,000 daily views at its peak in September 2021 and the most up to date figures available from the Northern Ireland Department of Health indicate that its COVID-19 dashboard had experienced over 1.5 million unique viewers worldwide as of May 2021.

We heard from both users and producers about the benefits of dashboards. For example:

- Dashboards can be more engaging for many users, who like to interact with the statistics and see them presented in a visual way (as opposed to tabular or textual forms)

- Dashboards can support the release of underlying data, letting others access them and add value through their own analysis

- While upfront resource is required for developing dashboards, and resource will be needed to maintain and improve them, many producers have found that using dashboards results in more efficient processes, allowing them to use analytical resource for other priorities

In light of the success of COVID-19 dashboards, lots of producers are planning to introduce dashboards to other statistics. For example, Public Health Scotland is consulting with its users, proposing a general move for its statistics away from reports towards dashboards and open data. The Department of Health in Northern Ireland recently published a new dashboard on cancer waiting times in place of its traditional pdf report. The Department has been working with its users to gather and respond to feedback on this new dashboard, and is planning to take a similar approach for other statistics in future.

Despite the benefits described above, we caution producers against automatically introducing dashboards or replacing existing statistics with dashboards without carefully thinking about the value they will add and their design. A dashboard in itself is not necessarily the answer to good communication of statistics; it needs to be well-designed and the reason for choosing a dashboard over other products should be clear and guided by user needs. Some attributes of the UK COVID-19 dashboard which we consider made it so successful are that:

- it responded to user needs as they changed throughout the pandemic – introducing new topics and measures over time, and engaging with users to obtain and respond to feedback

- it allows users to download the underlying data (we heard that it is particularly frustrating for some users if this option is not available on a dashboard)

- it includes a simple summary describing the latest headline figures

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- it provides a wealth of information about the data to support appropriate use

The multidisciplinary team which developed and now maintain the UK COVID-19 dashboard was instrumental in this success. This included statisticians and other experts on the data and its interpretation, as well as expertise outside the analytical community such as web developers and user researchers.

There are particular challenges with dashboards, which we are encouraged to find that producers are aware of and considering how to address. Accessibility is a key challenge when producing dashboards. In the UK, all content on public sector websites must legally meet accessibility criterion. This means that dashboards must be perceivable, operable, understandable, and robust, but dashboards built using popular 'off-the-shelf' software packages such as Power BI and Tableau can be difficult to make accessible. Even the UK COVID-19 dashboard is not fully accessible – though it is good to see an accessibility statement published which provides transparency on what steps the UK Health Security Agency (UKHSA) has taken to make the dashboard as accessible as possible and which areas are not fully accessible.

It can also be challenging to present sufficient insight, context and guidance on appropriate use alongside statistics in a dashboard. It is not yet clear how best to achieve this, and there is unlikely to be just one right answer, so sharing learning and good practice in this area will be important. The recently updated dashboard guidance from the Analysis Function Central Team is a helpful resource for producers, providing guidance on how to decide if a dashboard is the right tool for users. It also includes advice on important design elements to think about and information on accessibility. We would like to see the Analysis Function Team supplement this guidance with user research on what makes an effective dashboard, practical support on how to build one and guidance on user testing.

Statistical reports

For some users we spoke to, reports are still an important part of statistical publications. This is because they provide the opportunity for producers to include insightful commentary and background information about the statistics. Users told us that some statistical reports can be quite technical and therefore it is helpful when a summary with key points is included. As with dashboards, some users want to access the data as well as a report and can find themselves having to manually extract this information. Therefore, producers should always consider how to provide the underlying data, whether as a data table or open data, in addition to a report.

Social media (Twitter)

As discussed in our 2022 State of the Statistical System report, there has been an increase in the use of social media, in particular Twitter, to communicate statistics over the last few years. Most producers have organisational accounts which they use to share their latest release of statistics. We have seen some innovative uses of organisational accounts to engage with users of health and social care statistics. For example, during the pandemic Public Health Scotland used its Twitter account to share videos of statisticians talking about their statistics – such as this video of the Head of Profession for Statistics discussing changes to COVID-19 statistics or this

[video about the effect of COVID-19 on pregnancy](). Public Health Scotland found that these video tweets gained a high number of impressions (the number of times users saw the tweet) and a high engagement rate (including clicks, replies, retweets, likes and follows).

A particular phenomenon during the pandemic was the increase of "tweeting statisticians" – that is, government and non-government statisticians using personal Twitter accounts to communicate their statistics. The large followings that many of these people gained during the pandemic demonstrates that there is a public appetite for access to a reliable, expert voice on statistics (for example, during the pandemic [Clare Griffiths](), UK COVID-19 dashboard lead, and [Meaghan Kall](), an epidemiologist at the UKHSA, experienced ten- and 120-fold increases in followers respectively). Users also told us that they like this way of engaging with statisticians. Tweeting statisticians themselves told us about the many benefits they have experienced including:

- Raising awareness about and publicising statistics to a broader audience, particularly members of the public

- Summarising and explaining statistics in a succinct way

- Answering user questions and debunking common misconceptions about statistics

- Learning more about users – who they are and what they are interested in

- Personal development through following other accounts, and interacting with colleagues and other experts

- Humanising the work of statisticians – showing that there are real people behind the outputs

However, running a personal account on Twitter can be challenging. At times, Twitter can be a difficult environment and can lead to trolling or personal attacks. It can also be hard to explain complex information within short word limits and to mitigate the risk that tweets are taken out of context. Running a successful Twitter account takes time and effort and we heard that this is not always considered part of a statisticians' or analysts' role. There is also a burden on communications teams, who monitor tweets and may have to respond to media queries that arise from Twitter activity.

While organisations do have social media policies, we heard that these tend to focus on what not to do. There is therefore a gap in guidance about what *to do* in order to realise the many benefits listed above. Producers would appreciate more support, for example on handling challenging questions and comments. We would like to see guidance on running a personal Twitter account and examples of good practice provided for producers by the Analysis Function Central Team to support this engaging and effective way of communicating with the public about statistics.

> **Case study: Communicating COVID-19 statistics to a varied audience**
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> In May 2020, the Office for National Statistics (ONS) published the first statistics on COVID-19 infections in the community in England from the Covid Infection Survey (CIS). During 2020, the CIS expanded to become a UK-wide survey and provides a regular, timely insight into the prevalence of COVID-19 in the general population. In order to better understand who was using the statistics and how to meet their needs, ONS established a strategic development hub responsible for user engagement on the CIS. This team developed an engagement strategy, which aimed to identify and understand the needs of current and potential CIS users through a broad range of engagement activities. These activities included the establishment of a user group, regular technical seminars with government stakeholders, the use of web analytics, and ensuring that each interaction with users provided value, for example by offering one-to-one conversations with individuals who contacted ONS about the CIS.
>
> As a result of its engagement activities, ONS identified that the users of the CIS are extremely varied, including members of the public, government colleagues, academics and journalists. This means that a range of products are required, each targeted to different audiences. For example, for general users and the media, the weekly CIS bulletin and ONS's COVID-19 Insights tool provide a high level overview of the latest results. For more expert users, ONS publishes a range of technical outputs, including a methods report, quality information and technical articles about bespoke analyses, as well as making the underlying data available to support users to carry out their own analysis. ONS has also made use of blogs to communicate important technical detail in an accessible way and to myth-bust if there has been confusion about the statistics among the public. And finally, ONS has used both its organisational and personal staff Twitter accounts to share information with users of the CIS, as well as discussing the survey on its podcast, Statistically Speaking.

Minimising the misuse of statistics

A risk to health and social care statistics serving the public good is misuse, to accidently or deliberately misinterpret what statistics means. In early 2022, we explored this issue, prompted by the misuse of UKHSA statistics on COVID-19 infection rates by vaccine status. The UKHSA published the statistics with good intentions of supporting transparency, but the statistics were misused – for example, the figures were used to support anti-vaccine misinformation in podcasts and online. Misuse also occurred based on similar analysis published by Public Health Scotland, such as misuse in a US Senate committee hearing to claim that vaccines were causing mass infections.

We consider that there are three aspects to misinformation:

- The actor: the desire by some to deliberately misinterpret statistics to support a particular agenda or narrative

- The data: if taken out of context, data can be mobilised in a way that misleads

- The statistics producer: who has responsibility for decisions about how the data are analysed and presented, providing warnings against misinterpretation, and responding quickly to address issues when it is clear that data are being misused

Much of the focus when talking about misinformation is on the first of these – the actor. Yet misinformation is not always based on complete falsehood. Sometimes people have taken small elements of data out of context and placed undue weight on them. In other cases, there may be inadvertent misinformation, where data are misunderstood.

In the case of statistics on COVID-19 infection rates by vaccine status, we found that users had to work quite hard to find official figures and that understanding them was not easy for all users due to the technical nature of the reports they were published in. We welcomed changes which both UKHSA and Public Health Scotland made to the presentation of their analyses and accompanying blogs published to guide appropriate interpretation (blogs by UKHSA and by Public Health Scotland). We also supported producers' decisions, in light of changes to COVID-19 testing policies, to stop weekly reporting of these statistics due to uncertainties in the data resulting from policy changes and the potential for misinterpretation, particularly relating to vaccine effectiveness.

We recognise that combatting misuse is challenging and that it will not always be possible for producers to completely eliminate misuse. However, producers need to minimise the risk of misinterpretation and misuse by making it easy for people to find and understand objective, clear information. This can be achieved if producers are aware of the broader context they are working in – for example, in the case of the vaccination analysis described above, there was a heightened public interest in data and analysis during the pandemic. Producers should be agile in responding to public debates and consider the risks associated with the publication of their statistics in advance – depending on the level of risk, producers may need to take different approaches to how statistics are presented, for example it may be necessary to 'pre-bunk' anticipated misuse or misinterpretations. Producers should also ensure that any caveats are explained prominently alongside their analysis and consider the use of a blog, or similar explainer, to communicate technical content in a way which is easily understandable for a general user. Finally, it may be necessary for producers to collaborate across professional communities to decide on the best approach – for example, across the analytical, scientific and communications professions.

Annex: Approach to the review

An important part of this review involved talking to producers and users of health and social care statistics. Below is a list of the organisations we engaged with during the review. We would like to thank everyone who gave their time to speak with us.

- Care Inspectorate Scotland
- Department of Health and Social Care
- Department of Health (Northern Ireland)
- The King's Fund
- NHS England
- NHS Digital
- Nuffield Trust
- Office for National Statistics
- Public Health Agency
- Public Health Scotland
- Public Health Wales
- Scottish Government
- Scottish Parliament Information Centre
- Senedd Research
- Welsh Government
- UK Health Security Agency

In addition to the interviews above, we gathered evidence from other sources. This included written contributions from statistics producers and users, evidence gathered as part of our regulatory work during October 2021 – October 2022, and the Royal Statistical Society's COVID-19 evidence sessions.