# Analysis of UK reporting on health data

February 2021

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This report was developed by strategic communications consultancy, Portland Communications, on behalf of Understanding Patient Data.

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# 01 Executive Summary

# Research objectives







Analyse narratives and themes related to the use of health data in UK media reporting and public discourse, including how they have changed during COVID-19

Assess how UK media reporting on the use of health data influences public discourse Publish insights that can inform efforts to make the use of NHS health data more visible, understandable and trustworthy



# **Key findings**

# 1. Reporting on the use of health data is most positive when there is a tangible benefit for the health of individuals

- While more news stories were optimistic than negative, this was heavily driven by private companies reporting on successful outcomes, such as new medicines or products. These stories rarely explain the process behind the outcome, and so fail to drive widespread public awareness of the benefits of using health data.
- Positive reporting was also heavily driven by the potential for health data to help manage COVID-19. The pandemic has made the benefits of the use of health data clear to a wider audience and driven debate on the technicalities of regulation, opening up opportunities to increase general public awareness.



# 2. Reporting on the risks associated with the use of health data receives more cut-through with the general public than any other theme

- The media typically only analyse the process of using health data when something goes wrong, such as a data breach, driving a strong focus on risks within public discourse.
- In public discourse, the most widespread criticism emerges when private companies access data, despite few concrete examples of negative consequences. This is particularly true of companies who have been accused of misusing broader types of data in the past.





# **Key findings**

- 3. The topic of health data is highly politicised, often becoming a lens for criticism of broader issues, such as privatisation of the NHS or the use of other types of data
  - There is greatest public scrutiny when NHS data is involved particularly if it is being shared with international organisations.
  - In both reporting and public discourse, there is limited focus on the potential benefits to an individual from these partnerships.

- 4. There is limited focus on the role an individual can play in managing their own data, potentially reducing opportunities for wider public engagement
  - Reporting tends to position individuals as passive players, likely contributing to a sense of powerlessness and driving sentiments such as anger and fear in public discourse
  - In both media reporting and general public discourse, there is very limited focus on an individual's options for consent or potential involvement in shaping regulation.







### Research approach

Research question: How does greater visibility of health data issues in the UK media influence public discourse on health data?

Analyse **media reporting** on the use of health data to understand the sentiment, structure and themes of content available for public consumption

Review **social media conversation** on the topic of the use of health data to understand the influence of reporting on general public perceptions

This approach has two limitations:

- 1. While conversation on public social media platforms, such as Twitter, forms an integral part of public discourse, it is not necessarily fully representative of broader discussion or private perceptions of the use of health data.
- 2. Through analysing media and social media conversations simultaneously, comparing and contrasting, we can start to understand the relationship between the two. However, given the wide factors influencing public understanding, it will not give us full conclusive evidence of the precise causal impact media coverage has on public discourse and understanding.

Our definition of health data was based on the GDPR definition:

'Data concerning health' means personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.

In the process of our research, we refined this definition to:

- Exclude any macro level analysis of statistics on COVID-19 cases and deaths
- Include topical conversation around anonymised data, as it touched on relevant themes of personal data use and access

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# Research methodology

Stream	01. Media	02. Social Media	
Time period	1 May 2019 – 30 November 2020 (allowing analysis	of periods before and during the COVID-19 pandemic)	
Geography	UK (sampled to ensure inclusion of sources across regions and devolved nations)		
Data sources	TalkWalker with LexisNexis, drawing UK print, online and broadcast media	TalkWalker drawing in public social media content, largely from Twitter	
Approach to analysis	<ul> <li>Development of search string capturing conversation around the use of health data</li> <li>Exploratory research to determine the most relevant narrative strands appearing in the conversation</li> <li>Conducting analysis of top line metrics using TalkWalker</li> <li>Hand coding a sample of 350 articles for sentiment, narrative strands, and use of data mentioned</li> <li>Identifying and analysing a set of the most relevant case studies, focusing on the life cycle of stories within the media</li> </ul>	<ul> <li>Adaptation of search string to capture relevant social conversation around the use of health data</li> <li>Developing search strings to isolate conversation around specific narrative strands</li> <li>Conducting analysis of metrics from TalkWalker, including volume, influential posts and influential accounts</li> <li>Comparing social data to media data to isolate areas of greater and lesser pick up of media stories</li> <li>Using TalkWalker to supplement case study analysis, mapping factors influencing social media pick-up</li> </ul>	



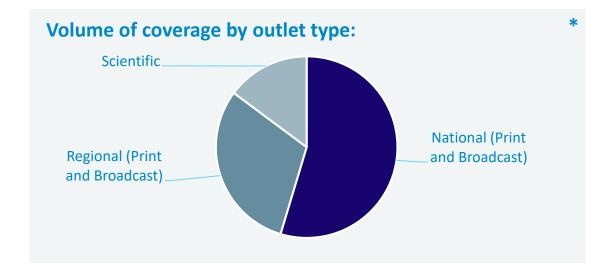
# 02 Media landscape

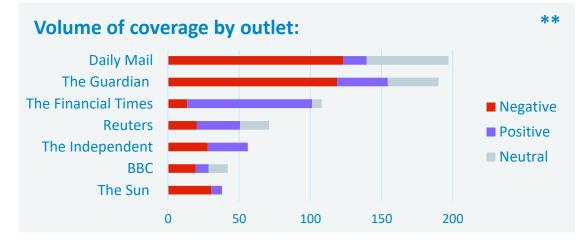
# Who is reporting on the use of health data in the UK?

A wide range of non-specialist outlets report on the use of health data. The Daily Mail and Guardian reported on the topic most regularly, often with a high level of scrutiny and criticism.

- Overall, 256 media outlets reported on the use of health data between May 2019 and November 2020. The majority of articles were in generalist outlets, covered by reporters across a variety or specialities

   including 'science', 'technology', and general news.
- Among national outlets, The Daily Mail reported on the topic of health data most frequently, closely followed by The Guardian. From both outlets, the majority of articles were negative (63% for both), indicating that these outlets tend to report with a high level of scrutiny.
- The Financial Times also reported on the topic regularly, taking a much more positive position (81% of articles were positive). This is likely due to their higher prioritisation of business and technological perspectives on the issue.
- Reuters and the BBC tended to be much more balanced in their reporting style. This is aligned to broader editorial stances positioning themselves as a primary source of neutral information for the public

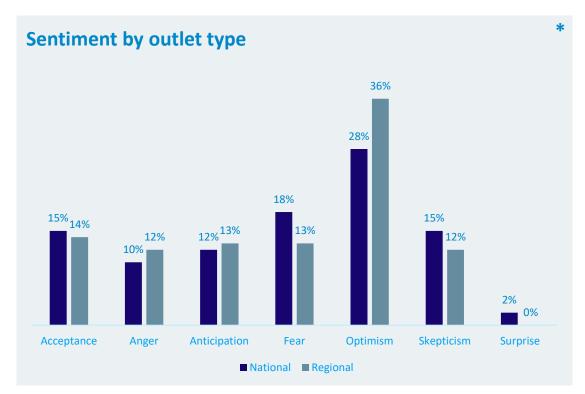




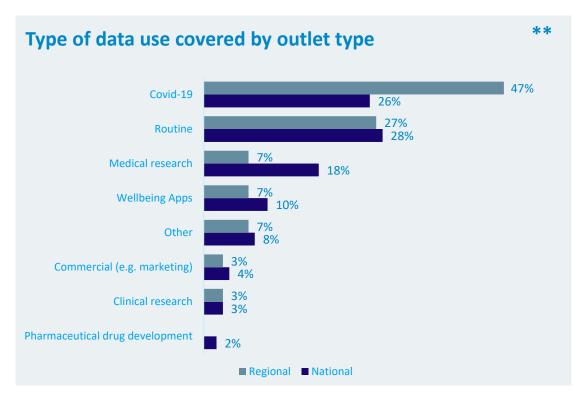


# Is there any geographic variation in reporting?

There are no significant differences in reporting between national and regional media outlets; however, regional outlets tended not to cover stories about research or drug development, which are likely to be perceived as national issues.



The sentiment of regional reporting is slightly more positive than national outlets.



This slight difference in tone is largely driven by a higher percentage of regional articles focusing on the benefits of using health data to manage the COVID-19 pandemic.



# Who is quoted as a spokesperson in media coverage?

While academics were the most quoted type of stakeholder in media coverage, no individuals consistently emerged as "go-to" authoritative experts able to share a balanced, constructive point of view on the issue.

Academics are the most regularly quoted spokespeople as a discipline in media coverage, suggesting a desire from journalists to access a relatively neutral commentator who can explain the technicalities of usage. However, academic figures tend to vary significantly and no consistent authority emerges from our analysis.

Spokespeople from private companies were also quoted regularly, either defending themselves against criticism or proactively showcasing the benefits of the use of health data.

The most regularly quoted individual spokespeople were generally political figures, who tend to convey a strong point of view on the issue:



Matt Hancock, Secretary of State for Health



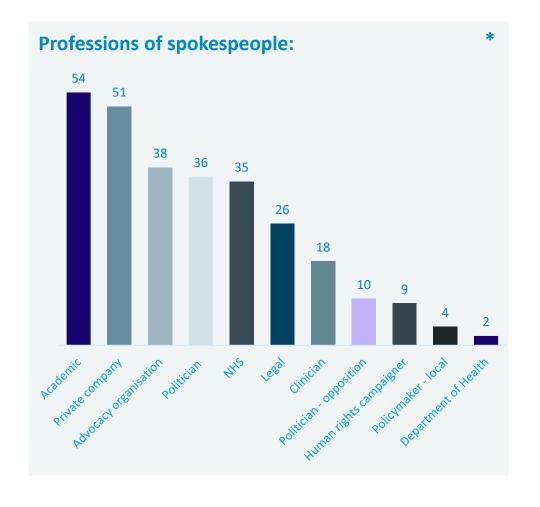
**Harriet Harman,** in her role as Chair of the Joint Committee on Human Rights



Lord Ara Darzi, in his role as Director of the Institute of Global Health Innovation at Imperial College London



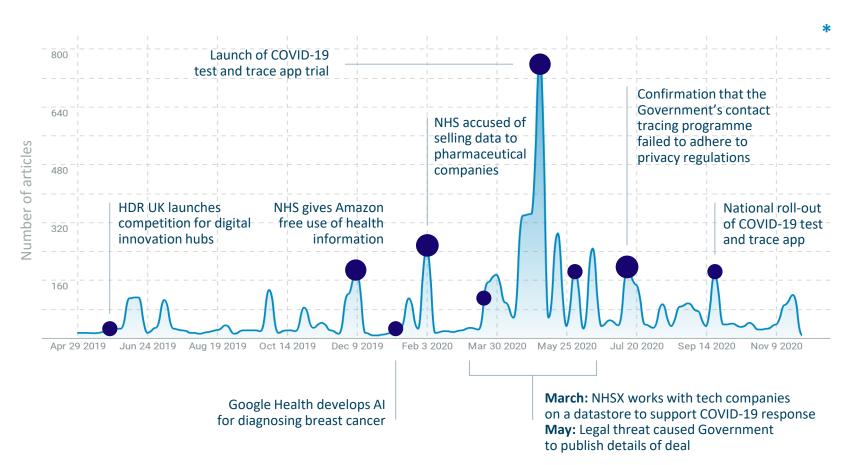
**Jeremy Corbyn**, ex-Leader of the Labour Party





# What is driving coverage of the use of health data?

The biggest peaks in media coverage are driven by critical reporting of an issue, such as the launch of the test and trace app



# Percentage of coverage related to each type of data use:

1. COVID-19	27%
2. Routine	26%
3. Medical Research	17%
4. Other	9%
5. Wellbeing apps	9%
6. Clinical Research	6%
7. Commercial	5%
8. Pharmaceutical Drug Development	1%

As a proportion of all articles coded, COVID-19 was the most common type of data use, followed by routine. Articles were coded for up to two types of data use, so many articles were coded as routine data, as well as another type of data use.



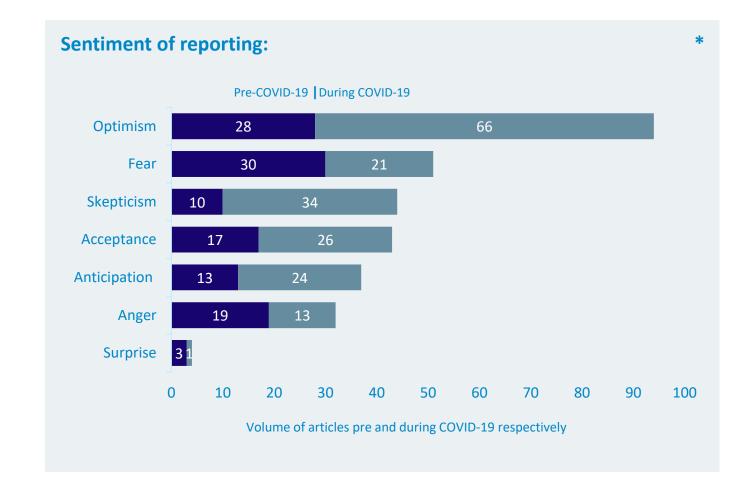
# What is the sentiment of media reporting on the use of health data?

Optimism is the most frequent sentiment of reporting, generally driven by discussion of the tangible benefits of data for managing the COVID-19 outbreak.

Optimism was the dominant sentiment of reporting, both before and during COVID-19. In the wake of the pandemic, over half of articles coded had a positive sentiment, with many of these related to the use of data for managing the pandemic.

Among negative sentiments, scepticism has increased most significantly as a proportion of reporting during the COVID-19 pandemic. This is largely driven by stories about the test and trace app. However, both fear and anger have decreased. One hypothesis for this shift in negative sentiment is that COVID-19 has highlighted a clear need for data use, but there is still a high level of scrutiny from the media.

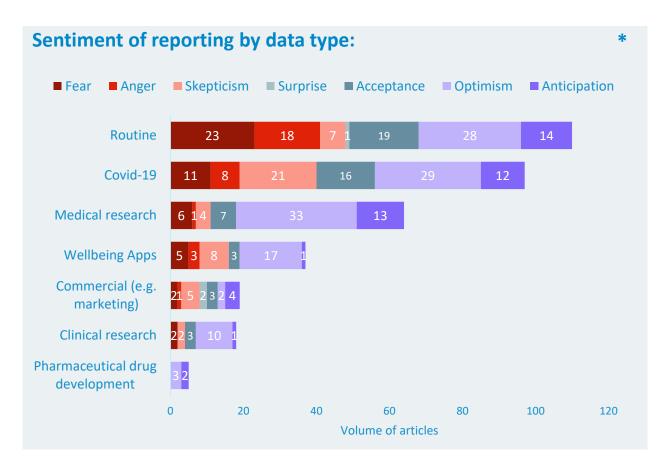
Meanwhile, surprise has been consistently the lowest sentiment, decreasing slightly during COVID-19.





# Does the sentiment of reporting vary depending on data type?

Reporting is most positive where there is a tangible benefit to an individual, such as a new treatment option.



Stories about medical research, clinical research and pharmaceutical drug development were the most positive in sentiment. This positivity tended to be associated with two key factors:

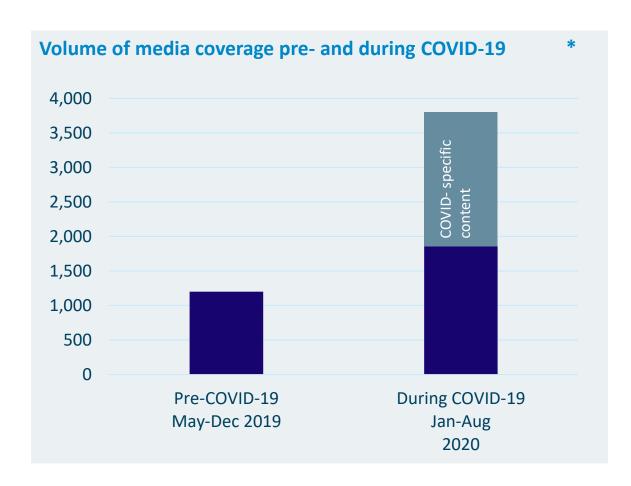
- Articles focused on a positive outcome, rather than going into the process of how data is used to achieve this. This was particularly the case in science outlets.
- 2. Coverage is often driven by proactive company press releases announcing successes, often found in trade outlets such as PharmaPhorum.

In comparison, the use of routine data is notably more debated in reporting, with a much greater split in sentiment. This is likely due to the fact that stories are more reactive, and often linked to an issue such as a data breach. With routine data, it is also harder to point to tangible benefits for an individual, rather than to the wider system.



# How has reporting changed since the outbreak of COVID-19?

During COVID-19 coverage on health data increased. This was largely related to the use of data to manage the virus, but stories on other types of data also increased.



The volume of media coverage focused on the use of health data increased overall during the COVID-19 pandemic, from 1,300 pieces pre-pandemic to 3,800 pieces during the pandemic.

Based on our coded articles, the majority of coverage (51%) following the pandemic specifically discussed data use in the context of COVID-19. However, the volume of conversation about other types of health data also increased, suggesting that the pandemic had the effect of generating broader discussion about the use of health data.

This is reflected in the increase in number of unique outlets from **145** pre-COVID-19 (May-Dec 2019) to **245 during COVID-19** (Jan-Aug 2020).

Over the next pages we look in more detail at how the themes of reporting and sentiment changed over this period.



# How has reporting changed since the outbreak of COVID-19?

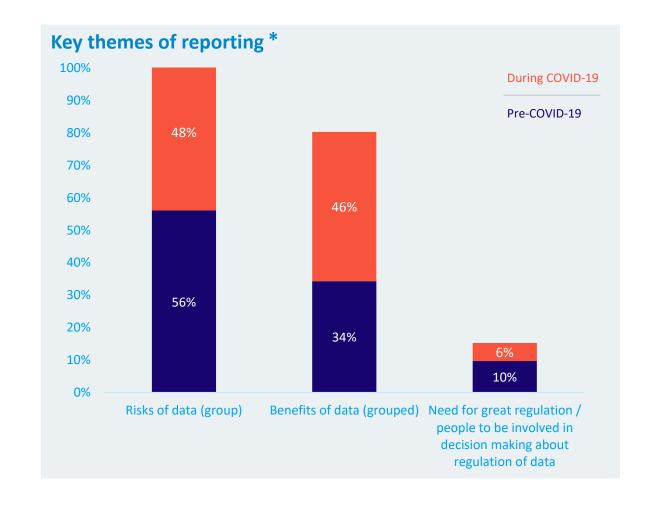
Overall, the proportion of conversation about benefits of using health data increased, but this is heavily driven by acknowledgment of the benefits of test and trace

Overall, the conversation around the risks of the use of health data has been dominant both before and during the COVID-19 pandemic.

However, during the COVID-19 pandemic, the proportion of articles about the benefits of data increased. This was, however, heavily driven by articles about the benefits of data to manage the COVID-19 pandemic.

The only other narrative strand to increase as a proportion of the conversation was around the risk that data will be used for non-health purposes, such as by the police for surveillance, or by insurance companies.

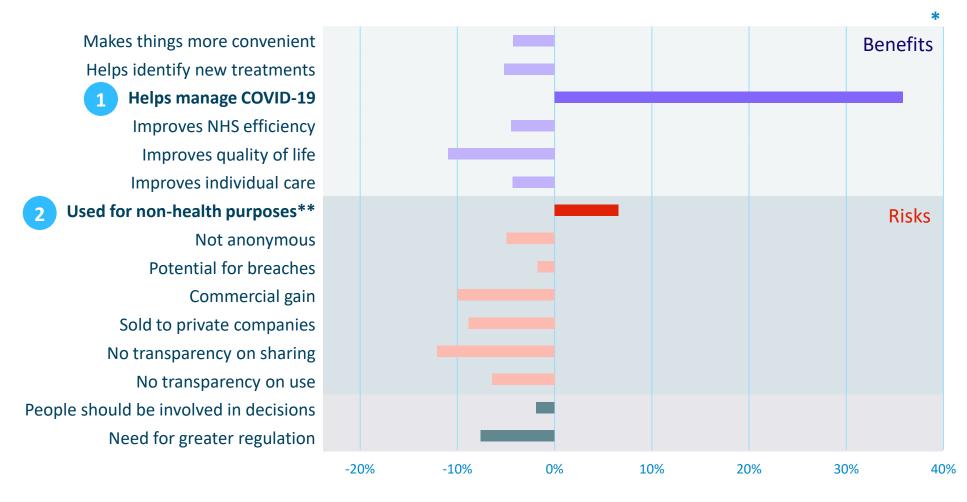
More nuanced arguments around the need for greater regulation decreased slightly as a proportion of conversation – however, as the overall volume increased, this means the number of articles stayed relatively stable.





# How has reporting changed since the outbreak of COVID-19?

Beyond reporting on the benefits of using health data to manage the pandemic, the only other narrative strand to increase as a proportion of conversation during COVID-19 was the risk that data could be used for non-health purposes.





# What is driving positive reporting on the use of health data?

Positive coverage is generally being driven by COVID-19 stories, as well as research success stories.

The breakdown of articles coded as anticipatory and optimistic is similar, with both sentiments predominantly associated with data used in the context of COVID-19 and medical research.

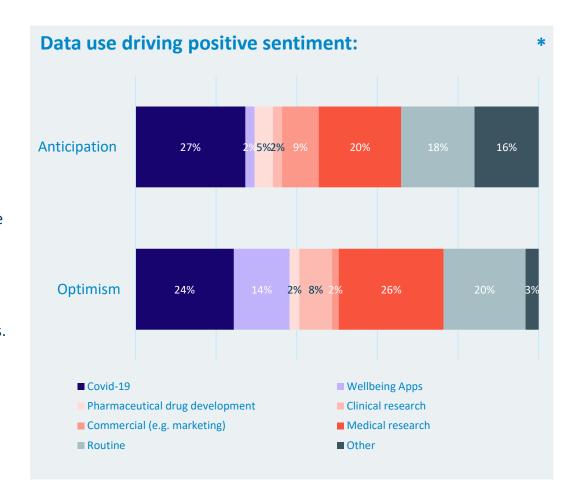
Optimism was more heavily associated with medical research, clinical research and pharmaceutical drug development, reflecting the excitement around innovative uses of data.

This also reflects the positive sentiment attached to stories driven by press releases from research communities and industry, which highlight research successes. This corresponds with the outlets driving positive stories, with business outlets such as the FT and health trade outlets such as PharmaPhorum, accounting for most stories (see next slide).

The anticipation and optimism around data and COVID-19 related predominantly to articles about the use of test and trace to manage the pandemic, but it also included some articles about the use of data in AI technology to better treat COVID-19 patients.

#### **Anticipation**

"Creating such a trusted and secure data-sharing architecture could also help health authorities develop more effective track and trace systems to combat future pandemics, Sir Tim said." – **FT, November 2020** 



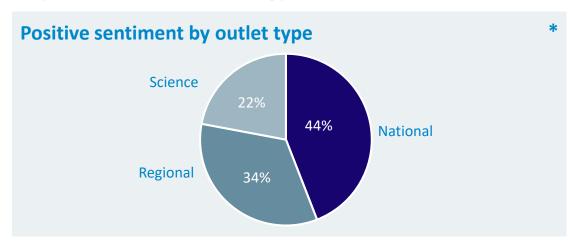


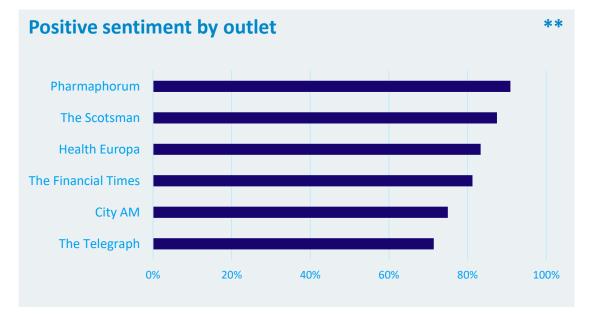
# What is driving positive reporting on the use of health data?

Health and business outlets were responsible for the majority of positive coverage.

The outlets reporting most regularly about the positive benefits of using health data were primarily specialist health outlets, such PharmaPhorum, Nature and Health Europa, as well as business outlets, such as The Financial Times, The Telegraph, and City AM. This suggests that outlets writing for an industry audience are more likely to write articles about the end use of health data and the potential benefits.

A significant proportion (34%) of positive reporting also came from local outlets. This positive sentiment may be skewed by the nation-wide public health campaign encouraging people to download the test and trace app, which saw many articles from local outlets writing positive stories about its use.





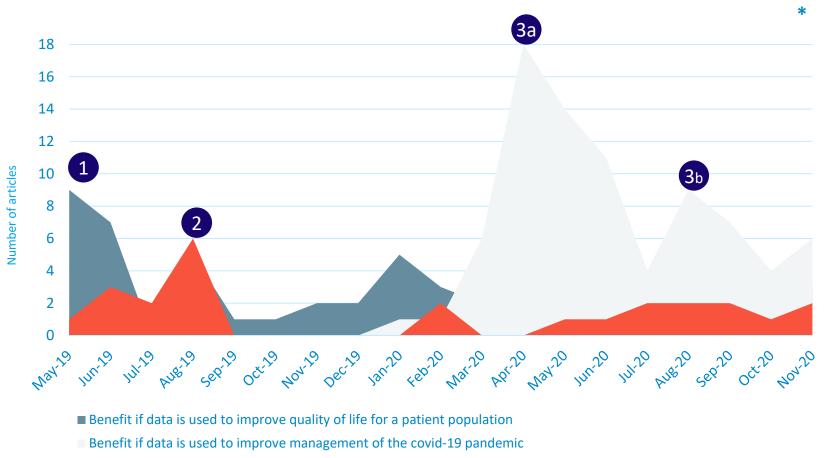
#### **Optimism**

"Staff describe the technology as a "potential lifesaver" - using hundreds of thousands of pieces of data, including blood tests and heart rate, it was able to work out whether a patient would develop acute kidney injury up to 48 hours in advance of it actually being diagnosed." – BBC, August 2019



# What is driving positive reporting on the use of health data?

Other than the launch on the test and trace app, peaks in positive reporting were not generally driven by external high-profile news moments, but rather a collection of several different stories coinciding.



■ Benefit if data is used to make things more convenient for people

Peak 1: At this peak there were several unconnected positive stories, on Health Tech start-ups such as <u>Closed Loop Medicine</u>, Bayer's start-up collaboration programme <u>G4A</u>, as well as other positive stories such as an <u>algorithm</u> to which can predict heart-attacks.

**Peak 2:** Similarly, at this point there was a peak of unconnected positive articles about Amazon moving increasingly into the health space, as well as patients being able to have control over their own personal data.

**Peak 3a:** This was the launch of test and trace pilot, which saw a number of positive articles which outlined the potential benefits. There was a second peak (**3b**) of similar coverage when the app was rolled out nationally.



# What is driving reporting on the risks of health data?

Fear and anger were predominantly driven by stories about the use of routine data, while reporting on COVID-19 data was more associated with scepticism.

Fear and anger were most likely to be associated with articles about the routine use of data. This is generally because routine data becomes more "news-worthy" when something goes wrong – for instance, many of these articles were related to data breaches.

Almost half of 'sceptical' coverage was focused on COVID-19. In many of these articles the potential benefit of data was clear (the ability to manage the pandemic); however, scepticism was driven by two separate factors:

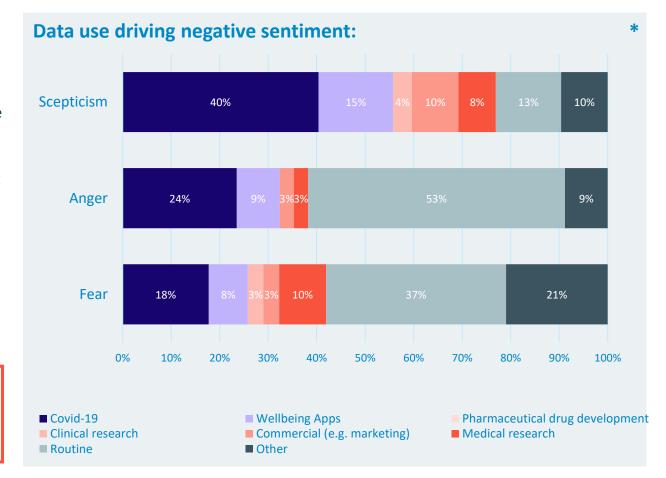
- 1. Commentators sceptical that the Government's approach to data handling would be effective in managing the pandemic
- 2. Commentators sceptical about the Government's claims that the data would be managed ethically and not compromise human rights

Articles about wellbeing apps also made up a significant proportion of sceptical coverage. This may be because the apps themselves could offer a clear benefit, but reporting is sceptical of their efficacy or the potential risks.

#### **Anger**

"The reckless behaviour of this government in ignoring a vital and legally required safety step known as the data protection impact assessment (DPIA) has endangered public health,"

- The Guardian, July 2020



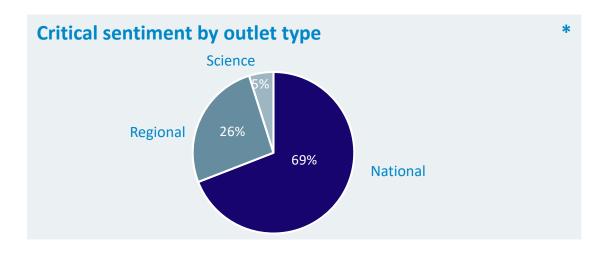


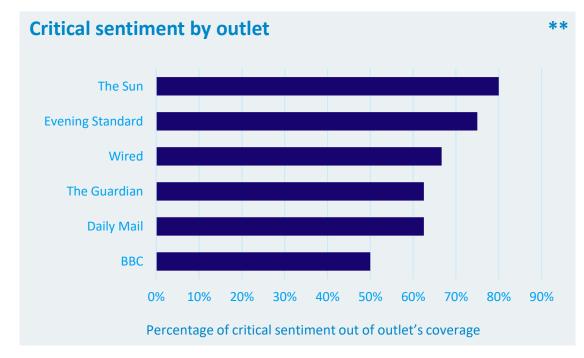
# What is driving reporting on the risks of health data?

Outlets such as the Sun and the Daily Mail have a high proportion of articles with a critical sentiment – however, fear, anger and scepticism is not limited to the tabloids.

Based on the sample of coded articles, tabloid outlets such as the Sun and the Daily Mail had a high proportion of articles with a critical sentiment (fear, anger or scepticism).

The high proportion of critical coverage from an outlet such as WIRED reflects the fact that specialised journalists are more likely to cover stories around health data in more detail and with a critical eye. Meanwhile, the fact that the BBC's coverage was 50% critical reflects the balance in its output.





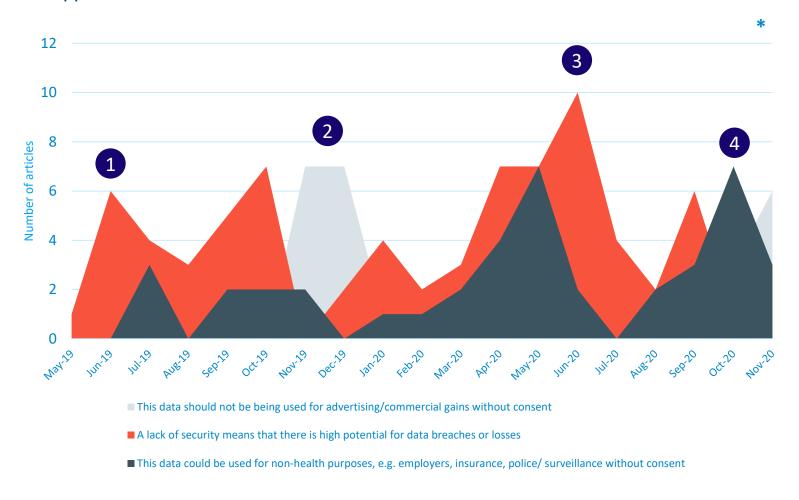
#### Scepticism

"The partnership [between Google and Ascension] is intended to use artificial intelligence to find patterns that could help doctors, but some are concerned about privacy and protecting patients' sensitive health information." – The Daily Mail, November 2019



# What is driving reporting on the risks of health data?

There are clear external moments driving peaks in coverage, including a number of concerns following the launch of the test and trace app.



**Peak 1:** This peak relates to a number of stories about medical implants being vulnerable to cyber attacks.

Peak 2: This peak corresponds to the Government's deal to give Amazon access to healthcare information from the NHS.uk website, which was reported in the media as the Government giving Amazon access to NHS health "data" for free. This story is analysed in more detail as a case-study later in this report.

**Peak 3:** Slightly after the test and trace pilot launched in April, there was a peak of stories with concerns over potential hacks of the contact tracing app.

**Peak 4:** This peak corresponds with reporting that police may have access to test and trace data.



03

# Cut-through to the general public\*

\*Mentions on social media are being used as a proxy indication of the general public's discussions and perceptions

# What are the key themes of conversation on social media?

The nature of conversation on Twitter surrounding the use of health data is highly political, with the 2019 General Election and government management of the pandemic featuring strongly



COVID-19 featured in an important way, as seen through the prevalence of test and trace, herd immunity and the Coronavirus Bill.

The 2019 election was a key driver for conversation around the use of health data with #GE2019 as well as #VoteLabour featuring in a number of tweets.

Concerns around the use of health data emerged in debates around data privacy, the role of private companies and the privatisation of the NHS.

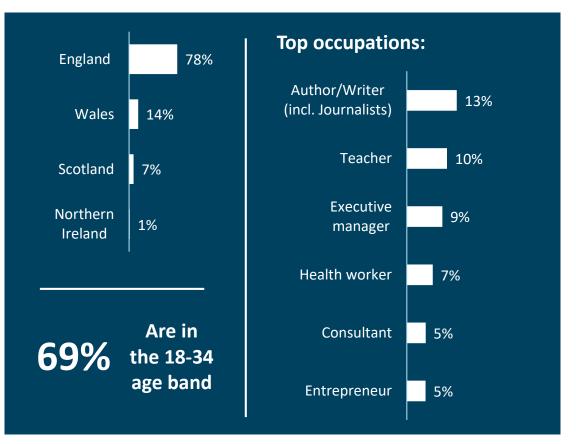
The positive impact and role that data can play was noted, however, through the prevalence of #datasaveslives.



# Who is talking about the use of health data on social media?

The conversation around the use of data is skewed towards a younger age group, and is influenced by the contributions of more informed audiences such as journalists, experts and politicians

#### **Demographics**



#### Influential accounts\*

**Dr Mike Galsworthy** Founder, Scientists4EU

\*WHAT!?\* "Amazon has been handed the keys to a trove of **NHS** data it can **use** to develop products to **sell** internationally without paying a penny to the UK. This one actually shocks me. This could contain very **personal data**. HUGE national security risk.

Jonathan Ashworth
Shadow SoS for Health

Our **NHS** must not be for **sale** in a trade deal with Trump, **patient data** must be safeguarded and our **NHS** mustn't be forced into buying expensive US

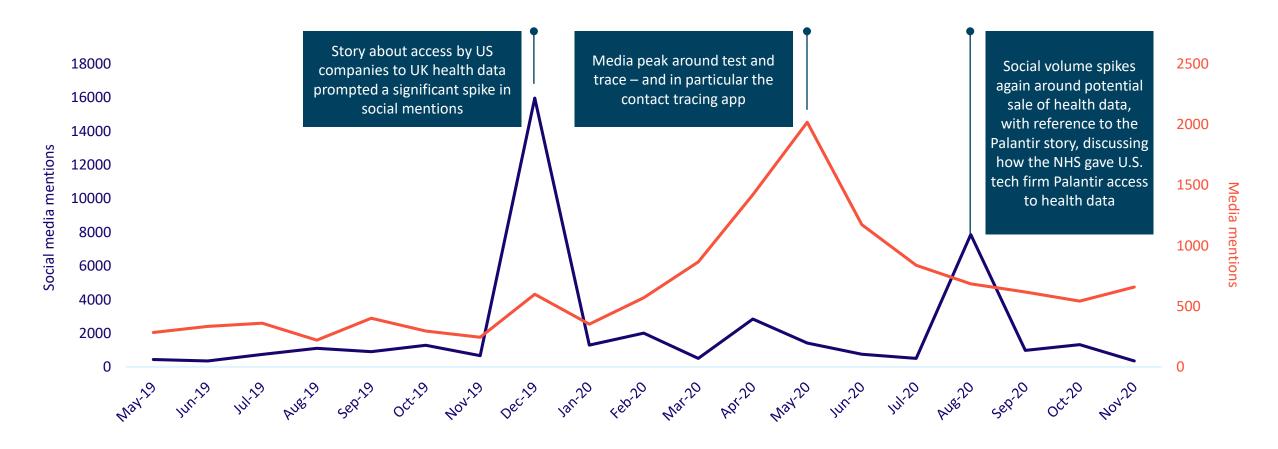
Carole Cadwalladr
Guardian Journalist

Oh. McKinsey's not just getting £560k for 6 weeks' work on creating 'vision' for new public **health** body. Also: '[It] is authorised to process **personal data** for test and trace personnel, contractors, customers, **users** and suppliers, for 7 years.'



# To what extent is media coverage driving social media conversation?

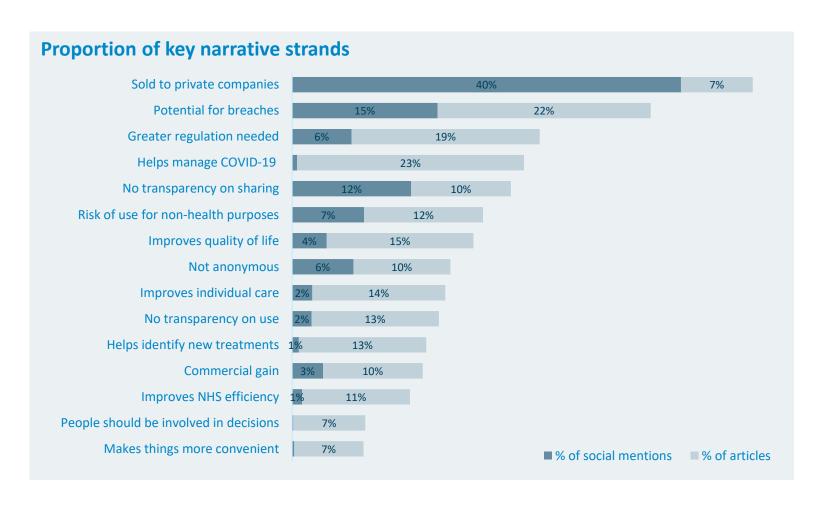
Not all media stories generate the same levels of social conversation, with stories around the sale of health data prompting the most significant spikes in social conversation. The peaks do not follow the same trajectories, and social media conversation increased rapidly at certain points, and dropped off quickly again.





# Is social media conversation aligned to the sentiment of reporting?

Discussion about the potential risks of using of health data dominate the conversation on social media, with very little focus on potential benefits.



Concerns around who has access to health data drives the majority of conversation on Twitter as users express unease around access by private companies, data being breached by security flaws, and a lack of transparency around who data is shared with.

There is limited follow-through explaining why this is a concern, with issues such as anonymity and data being used for non-health purposes featuring less prominently.

Despite trends in media reporting, the benefits relating to the use of health data don't cut through to the general public – even when related to management of COVID-19.

This is likely to be partly influenced by a tendency to use social media platforms, such as Twitter, to voice concern, rather than express support.

Issues such as citizen participation in decision-making on regulation generated close to no conversation on social media.



# Which stories gain the most traction on social media?

Critical stories gained the most traction across Twitter and represented most of the stories in the top-ten most widely shared hyperlinks.

Description of link	Headline	Number of times shared
Video by Mike Galsworthy	The NHS *is* for sale to the US and it starts with patient data.	1.9K
Article by New Scientist	Google gets green light to access five years of NHS patient data	399
Article by Euractiv	UK patient health data traded to US firms	172
Article by The Guardian	Patient data from GP surgeries sold to US companies	48
Article by New Scientist	NHS may use people's phone data to predict mental health issues	28
Article by The Guardian	UK government using confidential patient data in coronavirus response	26
Article by The Guardian	Revealed: how drugs giants can access your health records	22
Survey by Clinical Informatics for Mind and Brain Health	National Health Data Consent Survey	21
Article by Tech Crunch	UK's health data guardian sets a firm line for app development using patient data	20
Article by Tech Crunch	Google has used contract swaps to get bulk access terms to NHS patient data	17





# Which organisations feature in public discourse?

Companies criticised for their data practices dominated conversation on social media.

Major tech companies, including Google, Facebook and Apple featured most heavily in media coverage.

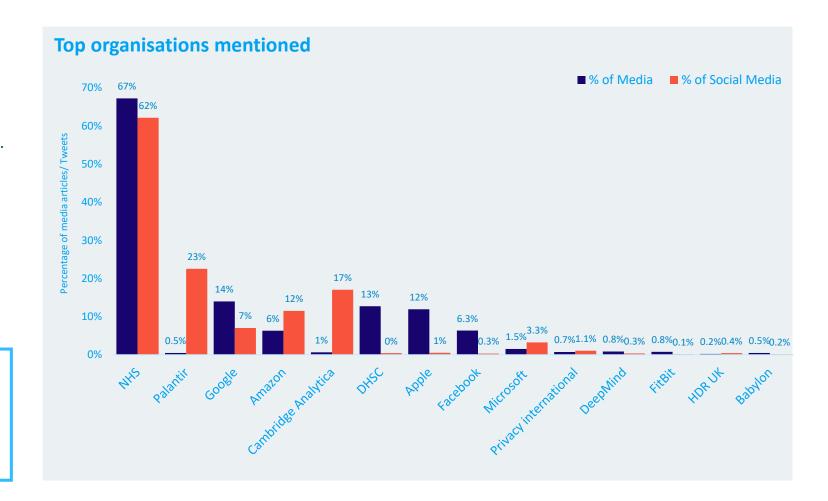
However, on social media, mentions of Palantir and Cambridge Analytica dominated conversation.

Amazon is also mentioned regularly on social media, with over 3,500 tweets in December 2019 related to a contract with the NHS – almost all posts were highly negative in sentiment.

The NHS was also mentioned in 67% of media articles and 62% of tweets.

#### Retweeted over 6,000 times:

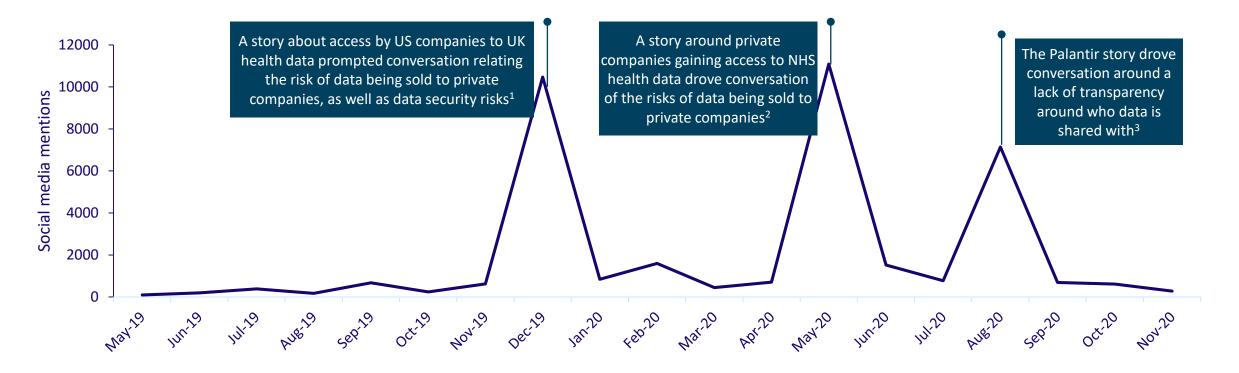
Is everyone aware that Johnson has quietly given Palantir (data-mining company linked to Cambridge Analytica) permission to access our personal health records? He did it apparently on the last day of Parliament so there could be no questions about it.





### Concerns around private companies accessing health data dominated conversation

Stories around private companies having access to or buying data were the key drivers of a conversation that was sceptical in overall tone. Conversation was not sustained, with mentions peaking and dropping rapidly following articles or certain tweets.



#### Stories which drove high numbers of mentions

<sup>1</sup>The Guardian, <u>Patient data from GP surgeries sold to US companies</u>, 7 December 2019

<sup>2</sup>Open Democracy, We need urgent answers about the massive NHS COVID data deal, 7 May 2020

#### Tweets which drove high numbers of mentions

<sup>3</sup>"Is everyone aware that Johnson has quietly given Palantir (data-mining company linked to Cambridge Analytica) permission to access our personal health records? He did it apparently on the last day of Parliament so there could be no questions about it.", 3 August 2020



# 04 Case studies

### Case studies – rationale for selection

#### 1. NHS gives Amazon free use of healthcare information

- The story could be **traced back to different sources** (the contract between the UK Government and Amazon; a letter to the EU commission)
- The news was reported by top tier outlets and engagement levels were high, despite relatively few publications.
- The story highlighted concerns about **transparency around how data would be used**, **privacy**, **data being used for commercial gains**, and the issue of **trust**.
- The story fed into broader debates around sharing NHS/ health data with private companies.
- The case study showed how lack of clarity about the type of data being shared (healthcare information provided on the NHS.uk website vs. medical records) in media coverage can lead to or enable conflation and confusion in public discourse.
- The UK election in December 2019 provided interesting **political context** for the story.

#### 2. Announcement of the COPI (Control of Patient Information) notices

- The announcement was reported by **online health journals/outlets**. Later articles that referenced the notices were published by **top tier and local outlets**.
- Unlike the other case studies, media coverage received relatively low levels of engagement and conversation remained confined to specialist circles.
- In contrast to the other case studies, reporting by media was neutral or positive in tone, in part, because the most prominent story focused on an example of the benefits of data sharing in a secure environment. The news was also more **technical** in nature and focused on process.
- The story spoke to key narrative strands of interest benefits of sharing data to **improve** the management of COVID-19 and to make the NHS more efficient.

#### 3. Launch of COVID-19 test and trace app

- The story represented the **highest peak in media coverage** over the period analysed, with a broad **range of outlets** reporting on the news.
- In addition to the high volume of coverage, articles had **high levels of engagement**.
- The case study highlighted concerns about the use of a centralised system in the first iteration of the app, potential for misuse of data or anonymous user data to be linked to individuals, and vulnerability to attack and fraud.
- A broad range of stakeholders were cited in coverage and a variety of individuals from different audience groups commented on the news on social media.
- The news broke out **during the COVID-19 pandemic** and showed how COVID-19 has increased conversation around the use of personal/health data.
- The UK government's decisions were **heavily scrutinised** and the story was often linked to other news stories, including the deal with Amazon.

#### Selection criteria for the three case studies:

- Complementarity of subject matter and focus on key themes relating to the central research question
- Variety in type and volume of media coverage
- Range of stakeholders involved, and spokespeople cited in coverage
- Impact on public discourse, assessed through engagement on social media
- Appeal to different audience groups
- Timing of stories (e.g. pre- and during COVID-19; around significant external events)
- Reference to source texts (e.g. government announcements, contracts)



# Case studies – overview of findings

- 1. The impact of media coverage on public discourse varied depending on a number of factors, including the type of story and timing of the news.
- Articles reporting on the NHS granting Amazon access to healthcare information provided on the nhs.uk website were published ahead of the 2019 general election, which explains high engagement levels and politicisation of the debate on social media. The story also fed into the broader conversation around sharing NHS data with private companies.
- Media coverage of the issuing of the COPI notices received the least attention on social media, with conversation remaining confined to specialist circles. This is likely to be in part due to the focus on technical processes in media coverage and less emphasis on benefits and risks.
- The launch of the COVID-19 test and trace app represented the highest peak in media coverage. News stimulated debate among a variety of stakeholders and attracted critical commentary online.

- 2. Negative sentiment is prevalent in social media conversation. Even when media coverage is balanced, social media users often focus on risks.
- Both the Amazon case study and the COVID-19 tracing app case study highlighted similar concerns among the public around privacy, transparency, vulnerability to attack and fraud, and personal data being used for commercial gains. Posts often expressed a lack of trust in government and made links between different stories.
- Coverage of the COPI notices had the lowest level of engagement on social media, suggesting that messages around the benefits of sharing health data are not cutting through to the general public to the same extent as those highlighting potential issues.

- 3. Both in media coverage and on social media, there is a lack of clarity about the type of data being used/ shared.
- This was most evident in the Amazon case study,
  where reference to "NHS data" in news headlines enabled
  a conflation of healthcare information provided on the
  NHS website and health data in public discourse. Despite
  some articles noting that the UK Government's deal with
  Amazon excluded health data, social media users voiced
  concerns about personal data being shared with the
  company.





NHS gives Amazon free use of healthcare information provided on the nhs.uk website

#### What was the story?

#### 8 - 14 December 2019: NHS gives Amazon free use of healthcare information

#### The story in short

In December 2019, two elements caused a spike in news coverage about Amazon being granted free access to healthcare information provided on the NHS.uk website. This did not include data from medical records. The Sunday Times showed details of the contract and level of access to NHS healthcare information, while PA news agency reported seeing a letter to the EU Commission lodging a formal complaint about the deal. The story was reactive in nature, with media interpreting key documents to shape coverage. Articles reflected and influenced a polarised debate, with few neutral commentators intervening to provide a balanced view. It also highlighted an underlying confusion about the definition of health data itself, with some media and commentators implying that Amazon was accessing people's health records.

#### Number of articles and overall engagement

- Number of articles 103
- Twitter shares 4.9K; Facebook shares 9.3K
- Total engagement across platforms 42.9K

#### **Key Narrative strands covered**

- There is a lack of transparency about how this data will be used
- This data should not be used for advertising/commercial gains without consent
- There is benefit if data is used to improve quality of life for a patient population
- There is benefit if data is used to make things more convenient for people



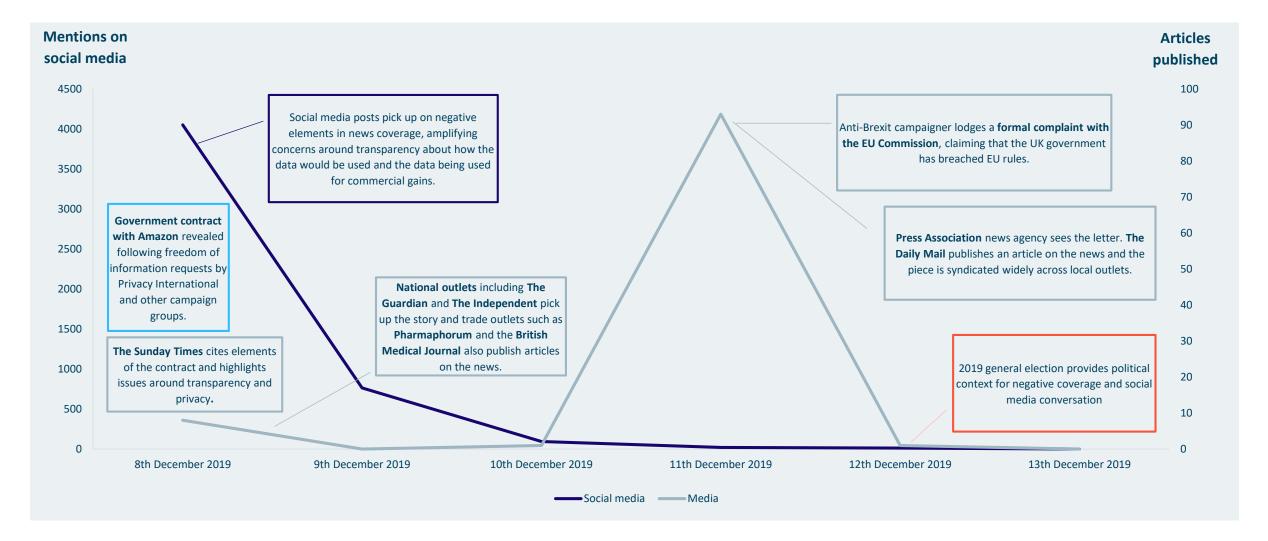


**Anger**, **fear**, and **scepticism** were dominant emotions in media coverage and on social media.

Some **optimism** was conveyed in media coverage through comments made by spokespeople from the UK government, NHS and Amazon, who noted the potential benefits of the deal.



# How did the story evolve?





Source text

Social Media conversation

External/environmental factors

Media coverage

# What were the drivers for media reporting?

The government contract with Amazon was revealed following freedom of information requests by <u>Privacy International</u> and other organisations, driving original pieces of news coverage. Controversies around the deal coincided with the upcoming UK general election, attracting media attention as outlets sought to capitalise on heightened political tensions.

<u>The Sunday Times</u> published the first piece on the news, citing elements of the contract. National and trade outlets including <u>The Guardian</u>, <u>The Independent</u>, <u>PharmaPhorum</u> and the <u>British Medical Journal</u> later published articles on the story. Though spokespeople from the UK government, NHS and Amazon, noted the potential benefits of the deal, and were cited in coverage, media framed the story in a negative light. Articles foregrounded concerns about transparency and privacy.

A second wave of coverage was sparked by a letter seen by the Press Association news agency, which showed that a formal complaint had been lodged with the EU Commission by an anti-Brexit campaigner. The PA piece was published by The Daily Mail and syndicated widely across local outlets.

Following the election on 12th December, coverage reduced to occasional references in broader articles. However, related content such as the <u>UK government's working with Amazon</u> and other private companies to manage COVID-19 has corresponded to further significant peaks in coverage after this period.



#### Which pieces of media coverage received most engagement?

- Articles that picked up information from the source (The Sunday Times, Press Association) and provided critical commentary had the highest engagement, while more neutral pieces (the BMJ) attracted less engagement.
- Media coverage foregrounded the issue of Amazon profiting from the deal.
- The use of the term "data" in headlines led to a lack of clarity around the type of information shared and potentially fueled negative sentiment online.

#### **Engagement figures of most shared articles on social media**



Total engagement – 85.3K Twitter shares – 45.6K Facebook engagement – 39.3K



Total engagement: 41.3K Twitter shares – 5.1K Facebook engagement – 37.5K



Facebook engagement – 48.5K





#### Key themes in social media conversation

- The issue of NHS data being used for commercial gains was a key theme, with tweets linking the Amazon story to the UK government selling health data to the US and international companies. Politicians, anti-Brexit campaigners, journalists, doctors, legal professionals and public health activists were among those voicing concerns.
- Questions around privacy were also highlighted on social media. While
  most media coverage explicitly mentioned the exclusion of health data
  within the article, headlines referred to "NHS data" and were therefore
  misleading. This enabled conflation or confusion around the type of data
  being shared, allowing negative commentary to escalate on social media.
- Political motivations were clearly a significant factor driving the social media conversation. Individuals and organisations expressed concerns about transparency and a lack of trust in government, with some tweets directly referencing the upcoming election. Labour politicians and supporters used the story as a hook to launch criticism against the government.



2 extremely alarming stories about NHS health data this am. Leaked docs last week showed NHS data key part of US trade deal. @tobyhelm reveals anonymised NHS data has \*already\* been sold to US drugs companies. There is \*no such thing\* as anonymised data



9:25 am · 8 Dec 2019 · Twitter for iPhone

6.2K Retweets 383 Quote Tweets 7.6K Likes

And then this. Revealed under FOI: Matt Hancock gave entire contents of publicly funded NHS website to Amazon to do whatever it wants with it. Both stories frankly unbelievable. If this is happening \*before\* a new US trade deal, what on earth lies ahead?



Amazon ready to cash in on free access to NHS data

Amazon has been handed the keys to a trove of NHS data it can use to develop

products to sell internationally without paying a penny to the UK.A government

& thetimes could

9:31 am · 8 Dec 2019 · Twitter for iPhone

3.3K Retweets 205 Quote Tweets 3.6K Likes



Matt Hancock has handed over a treasure trove of NHS healthcare data to Amazon for free. Extraordinary. You wouldn't trust this government to negotiate for you at a car boot sale. God help us if they are put in trade negotiations with Donald Trump's US.

9:52 am · 8 Dec 2019 · Twitter for Android

3.6K Retweets 219 Quote Tweets 6.2K Likes



Tories are giving NHS data to Amazon for free, documents reveal

The US company will be able to access all NHS patient data including without limitation symptoms, causes, and definitions

#VoteLabour #GE2019



Tory government giving NHS data to Amazon for free, official . US company will be able to access all 'healthcare information, including without limitation symptoms, causes, and definitions  $\mathscr S$  independent.co.uk





39 Victoria Street London SW1H 0EU

To:
Organisations providing health services
General Practices
Local Authorities
Arm's Length Bodies of the Department of Health and Social Care

20 March 2020

Dear All,

#### Covid-19 – Notice under Regulation 3(4) of the Health Service Control of Patient Information Regulations 2002

The health and social care system is taking action to manage and mitigate the spread and impact of the current outbreak of Covid-19. Action to be taken will require the processing and sharing of confidential patient information amongst health organisations and other bodies engaged in disease surveillance for the purposes of research, protecting public health, providing healthcare services to the public and monitoring and managing the Covid-19 outbreak and incidents of exposure.

I am therefore writing to inform you that I am serving notice under Regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (**COPI**) to require organisations to process confidential patient information in the manner set out below for purposes set out in Regulation 3(1) of COPI.

This Notice **does not** apply to NHS Digital or NHS England & Improvement, which are subject to separate notices under COPI.

# Announcement of the Control of Patient Information (COPI) notices

#### What was the story?

18 March – 3 April 2020\*: COPI notices relax rules on sharing confidential patient information in England

#### The story in short

In March 2020, the UK Government <u>issued a Control Of Patient Information notice</u> (see also <u>here</u>) to healthcare organisations, GPs, local authorities and arm's length bodies, stating that they should share information to support efforts against COVID-19. The news was reported by a number of health journals/outlets, including <u>BMJ</u>, <u>Pulse Today</u>, <u>Digital Health</u> and <u>Public Technology</u>. While these articles were news driven and technical in nature, some later pieces referencing the notice were more analytical. An article by <u>The Economist</u> on how COVID-19 has encouraged a new way to study medical records, for example, highlighted the advantages of sharing data within secure environments.

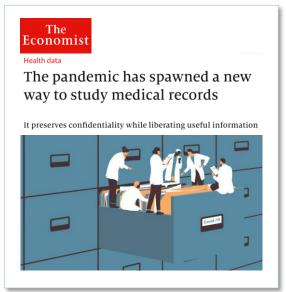
#### Number of articles and overall engagement

- Number of articles 4 (5 including later Economist piece)
- Twitter shares 87; Facebook shares 16
- Total engagement across platforms 156\*\*

#### **Key Narrative strands covered**

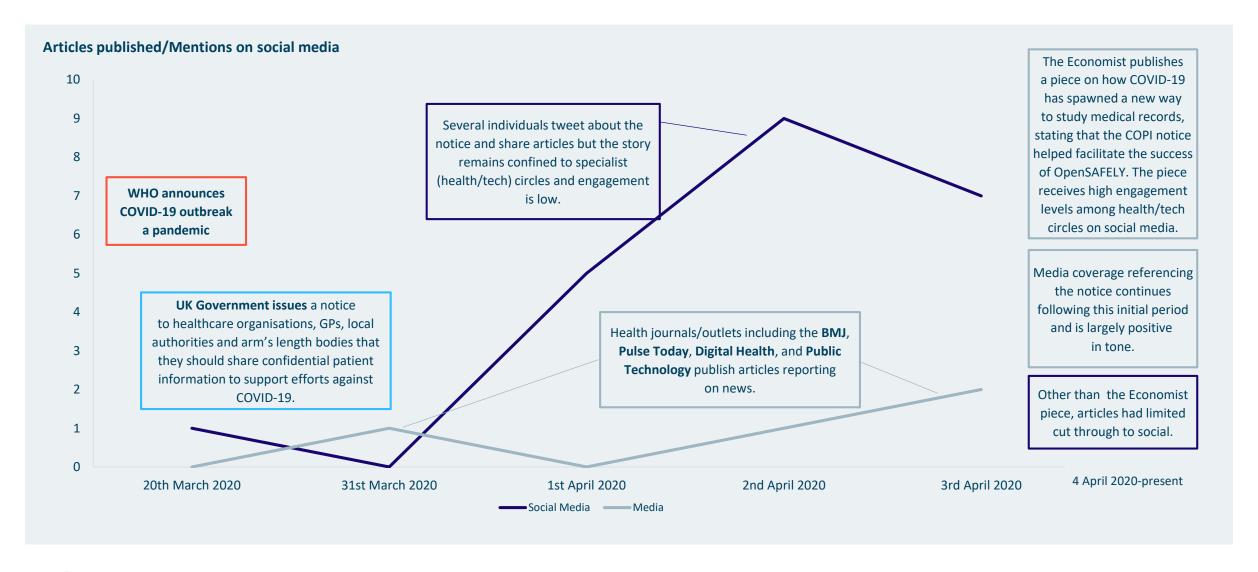
- There is benefit if data is used to make the NHS more efficient
- There is benefit if data is used to improve management of the COVID-19 pandemic
- There is benefit if data is used to improve quality of life for a patient population





Media coverage was either **neutral** or **positive** in tone, highlighting the role of the COPI notice in facilitating data sharing and processing to help manage the COVID-19 pandemic.

# How did the story evolve?





Source text

Social Media conversation

External/environmental factors

Media coverage

# What were the drivers for media reporting?

Following the issuing of the notice in March 2020, several health journals/outlets including the <u>BMJ</u>, <u>Pulse Today</u>, <u>Digital Health</u>, and <u>Public Technology</u> published articles on the topic. <u>Public Technology</u> and <u>Express and Star</u> later reported on the extension of the notice until 31 March 2021. Articles were factual and neutral in tone.

There has been a steady flow of articles referencing the notice following the initial announcement, including analytical pieces, as well as national and local news stories. Coverage has been largely positive, especially when associated with the benefits of being able to share health data efficiently within secure environments, particularly with respect to managing the COVID-19 pandemic. Notably:

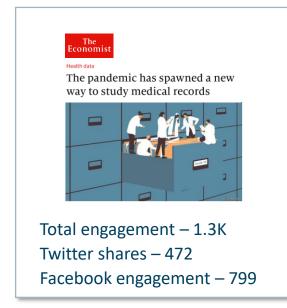
- The Economist and Yorkshire Post highlighted the role of the COPI notices in facilitating data sharing and processing for the OPENSAFELY platform.
- Manchester Evening News published a piece about the Greater Manchester Care Record scheme, noting that the initiative was supported by the COPI regulations.
- <u>PharmaPhorum</u> published a piece on research looking at the impact of COVID-19 on the public's health data sharing concerns, noting the issuing of the COPI notice.
- <u>The HTN</u> and <u>Computer Weekly</u> referenced COPI in articles on the government's new Data Strategy for Health and Social Care.
- <u>Press Association</u> published a piece that was syndicated across local outlets, which cited Matt Hancock's comments about more technology and data use in the NHS at the London Tech Week conference. During a keynote speech, he highlighted the COPI notice in the context of using data as an asset while protecting privacy.



#### Which pieces of media coverage received most engagement?

- Articles covering the initial announcement received relatively low levels of engagement. This is likely to be due to the technical nature of the pieces and the publication of the news at a time when public attention was focused on the impact of the lockdown.
- Later pieces referencing the notice had higher levels of engagement but the conversation on social media remained largely confined to specialist (health/tech) circles.

#### Engagement figures of most shared articles on social media











#### Key themes in social media conversation

- The benefits of sharing data to help manage the COVID-19
   pandemic was highlighted on social media. However, media outlets, health professionals and tech experts/organisations, were the most prominent groups participating in the conversation, suggesting that these messages may not be cutting through to broader audiences.
- Tweets sharing articles referencing the change in regulations also noted how data and technology can help inform care and treatment.
- The role of the COPI notices in facilitating the OpenSAFELY project was highlighted in The Economist piece and by the outlet on Twitter. Individuals commenting on the news, however, focused on the success of the platform and made broader comments about the advantages of sharing health data while protecting privacy.



New powers have been given to @NHSDigital as part of measures to help counter the spread of Covid-19.

Read more here - ow.ly/F67o50yOIBV



11:15 am · 18 Mar 2020 · Hootsuite Inc.

3 Retweets 3 Likes

The Economist ②

@TheEconomist

In Britain, notices signed by the health minister have made it much easier for teams of researchers to access and process health data



It preserves confidentiality while liberating useful information & economist.com

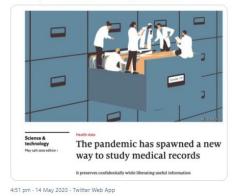
6:41 PM · May 16, 2020 · SocialFlow

34 Retweets 1 Quote Tweet 87 Likes



"Incentives created by the pandemic, and the ingenuity of the group [led by @BenGoldacre] of epidemiologists and data scientists" economist.com/science-and-te... @TheEconomist

massive analysis on the data in situ of ~17 M people and ~6,000 #COVID19 deaths @UniofOxford





30 Retweets 2 Quote Tweets 59 Likes

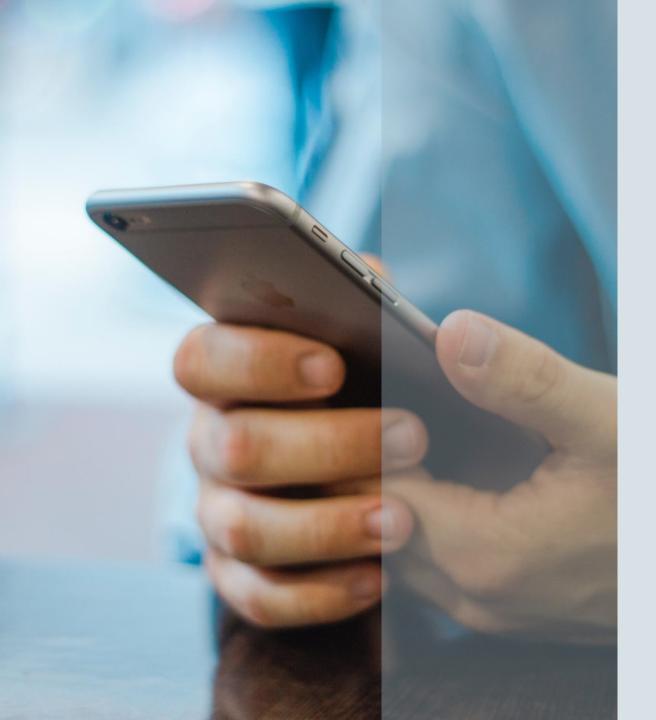
Great story about our new OpenSAFELY project in @TheEconomist today.

It really gets to the core: by using OPEN collaborative approaches from the software development community, and LISTENING to privacy concerns, we have DELIVERED, in the toughest space.

6:43 pm · 14 May 2020 · TweetDeck

14 Retweets 3 Quote Tweets 43 Likes





Launch of COVID-19 test and trace app

#### What was the story?

4 -10 May 2020: Launch of COVID-19 test and trace app trial

#### The story in short

The COVID-19 test and trace app trial in the UK represents the most significant spike of coverage within the period analysed under the scope of the report. The app was heavily scrutinised, with each step of the process attracting commentary and analysis by media and stakeholders, and the app becoming a central topic of government press briefings. Articles highlighted concerns about the use of a <u>centralised system</u> in the first iteration of the app, potential for <u>misuse of data</u> or <u>anonymous user data</u> to be linked to individuals, and <u>vulnerability to attack and fraud</u>. Commentators also regretted <u>the lack of clear benefit</u> for users in early versions of the app.

#### Number of articles and overall engagement

- Number of articles 346
- Twitter shares 1.1K; Facebook shares 3.2K
- Total engagement across platforms 20.5K

#### **Key Narrative strands covered**

- There is a lack of transparency about how this data will be used
- There is a need for greater regulation around the use of personal health data
- A lack of security means that there is high potential for data breaches or losses
- There is a risk that data won't be anonymous
- There is benefit if data is used to improve management of the COVID-19 pandemic



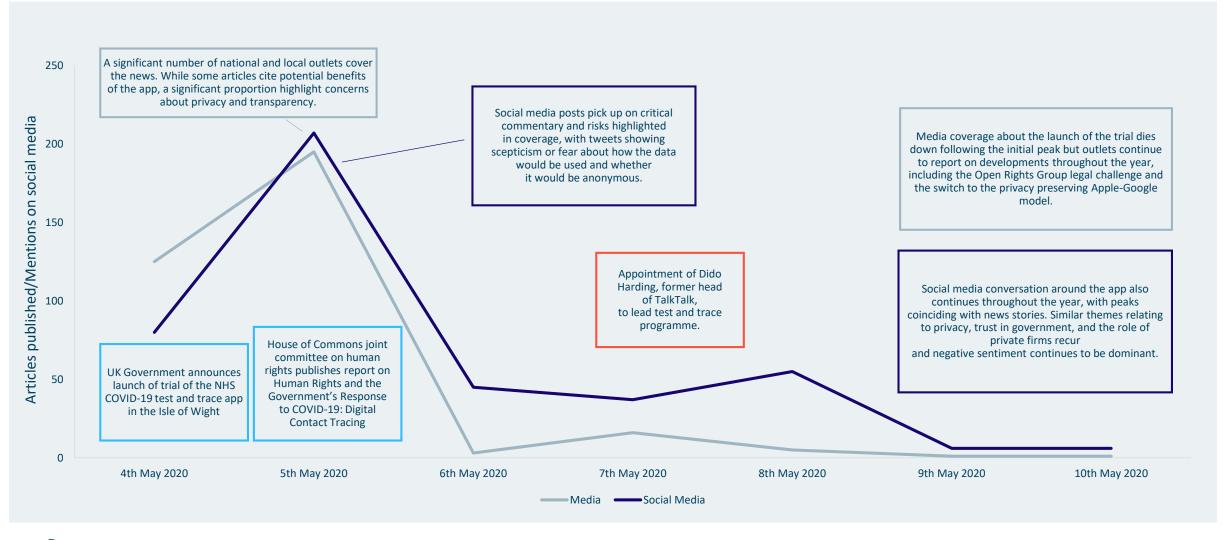


**Anger**, fear, and scepticism dominated social media conversation and was present in the majority of media articles.

**Optimism** and **anticipation** were conveyed through the comments of key spokespeople, who highlighted the potential benefits of the app to help manage the pandemic. Only a small proportion of tweets were characterised by these sentiments.



#### How did the story evolve?



Understanding Patient Data

Source text

Social Media conversation

External/environmental factors

Media coverage

# What were the drivers for media reporting?

The most significant spike in coverage over the period was in early May around the launch of the COVID-19 test and trace app trial in the UK. While some articles were neutral and explanatory in tone (e.g. <u>Financial Times</u>, <u>BBC</u>), most highlighted concerns about privacy and the use of personal data. The use of a <u>centralised system</u>, potential for <u>misuse of data</u> or <u>anonymous user data</u> to be linked to individuals, and <u>vulnerability to attack and fraud</u>, were cited as key concerns.

The potential benefits of the app to help manage the pandemic were highlighted by key spokespeople, who were cited in coverage. Health Secretary Matt Hancock emphasised the responsibility of individuals to download the app to protect their own health and that of the community. Members of the public were thereby positioned as playing an active role in downloading the app to tackle COVID-19. Other senior figures such as Matthew Gould, Chief Executive of NHSX, also stated that the app would work together with other public health measures to contain the spread of COVID-19.

Some articles noted a <u>report</u> from the House of Commons joint committee on human rights, which stated that the NHSX app did not sufficiently protect the right to privacy and a lack of data protection measures could make it illegal. MPs and campaigners urging the government to put safeguards in place to protect individual privacy were <u>cited</u> in coverage.

Following growing scrutiny and media attention, the government switched from the centralised model to the <u>privacy preserving Apple-Google model</u>. While this led to another wave of coverage, there has been less focus on data following the switch. Media have also reported on other new elements of the story after the initial peak, such the <u>Open Rights Group legal challenge</u> and the Government's <u>collaborations with private companies</u> to bolster the test and trace programme.



#### Which pieces of media coverage received most engagement?

- Media coverage that received highest levels of engagement included both balanced pieces by top tier outlets and critical pieces that highlighted potential problems.
- Overall engagement in the story was high. However, engagement in individual pieces was lower than would be expected. This is likely to be due to the significant number of articles published, meaning that people were engaging with various sources.
- Though a large number of local outlets published stories on the news, these had low levels of engagement on social media.

#### **Engagement figures of most shared articles on social media**



Total engagement – 6.7K Twitter shares – 841 Facebook engagement – 5.8K



NHS Covid contact-tracing app could be ILLEGAL and will cause chaos for Brits' foreign travel because it's incompatible with Apple-Google system, warn critics as it goes live on the Isle of Wight

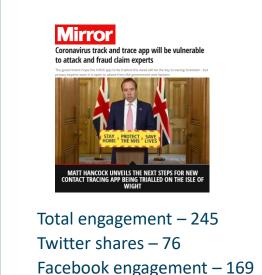
- . The NHSX contact-tracing app will first be given to NHS staff on Isle of Wight, then to the public on the island
- . If it works as an alert system for COVID-19 it will be used nationally in the UK as part of 'test, track and trace' NHS insists the app won't collect personal identifying information but merely a log of Bluetooth connection
- . It asks users for the first half of their postcode and whether they have symptoms, but no name or address The NHS track-and-trace app considered vital to getting the UK out of coronavirus lockdown could be illegal and

The software will be tested on the Isle of Wight from this morning onwards - but there are growing concerns about

Total engagement – 2.3K Twitter shares – 54 Facebook engagement – 2.2K



Total engagement – 297 Twitter shares - 114 Facebook engagement – 183





#### Key themes in social media conversation

- Conversation on social media to some extent reflected the story portrayed by the media. Tweets sharing coverage cited concerns about transparency, privacy, and vulnerability to attack and fraud, which were noted in media coverage. A broad range of individuals and organisations commented on the app and shared coverage, including MPs, journalists, political activists, legal experts and public health professionals.
- The discussion was, however, less balanced on social, with the majority of tweets showing scepticism or fear about how the data would be used and whether it would be anonymous. Only a few stakeholders voiced support for the app on Twitter.
- A large number of posts expressed a lack of trust in government, with some appearing to be politically motivated.
- Apprehensions about **sharing personal data with private companies** also came up in conversation, as individuals linked the launch of the app to other news stories, such as the <u>appointment of Dido Harding</u> to lead the test and trace programme and the <u>government's deal with Amazon</u>.









6:26 pm · 4 May 2020 · <u>Twitter Web App</u>

147 Retweets 5 Quote Tweets 294 Likes



# 05 Key findings

# **Key findings**

# 1. Reporting on the use of health data is most positive when there is a tangible benefit for the health of individuals

- While more news stories were optimistic than negative, this was heavily driven by private companies reporting on successful outcomes, such as new medicines or products. However, these stories rarely explain the process behind the outcome, and so fail to drive widespread public awareness of the benefits of using health data.
- Positive reporting was also heavily driven by the potential for health data to help manage COVID-19. The pandemic has made the benefits of the use of health data clear to a wider audience and driven debate on the technicalities of regulation, opening up opportunities to increase general public awareness.

# 2. Reporting on the risks associated with the use of health data receives more cut-through with the general public than any other theme

- The media typically only analyse the process of using health data when something goes wrong, such as a data breach, driving a strong focus on risks within public discourse.
- In public discourse, the most widespread criticism emerges when private companies access data, despite few concrete examples of negative consequences. This is particularly true of companies who have been accused of misusing broader types of data in the past.





# **Key findings**

- 3. The topic of health data is highly politicised, often becoming a lens for criticism of broader issues, such as privatisation of the NHS or the use of other types of data
  - There is greatest public scrutiny when NHS data is involved particularly if it is being shared with international organisations.
  - In both reporting and public discourse, there is limited focus on the potential benefits to an individual from these partnerships.

- 4. There is limited focus on the role an individual can play in managing their own data, potentially reducing opportunities for wider public engagement
  - Reporting tends to position individuals as passive players, likely contributing to a sense of powerlessness and driving sentiments such as anger and fear in public discourse
  - In both media reporting and general public discourse, there is very limited focus on an individual's options for consent or potential involvement in shaping regulation.







#### Key recommendations



SUPPORT GREATER CLARITY IN REPORTING

Support journalists to provide greater clarity, particularly around the differences between health data and other less 'sensitive' forms of information - minimising the uncertainty that drives negative public sentiment, while supporting journalists' ability to provide scrutiny



**ELEVATE PATIENT VOICES** 

Facilitate and encourage patient involvement in public discourse around health data utilisation by offering training to PAGs and patient influencers to act as spokespeople to articulate the benefits and risks of health data to patients



CREATE MECHANISMS FOR PUBLIC ENGAGEMENT

Showcase mechanisms for the public to share opinions on regulation and rights around consent. COVID-19 provides a significant opportunity to drive general public awareness of the benefits to an individual of the use of health data, and should be used as an example for talking about benefits in other areas



REVEAL THE PROCESS BEHIND SUCCESSES

Increase awareness of the benefits of responsible use of health data by focusing on examples of tangible positive outcomes for patients and showcasing how access to data facilitated this success



# 06 Appendix

# Methodology

Media analysis	Social media analysis	Case studies
<ul> <li>Using TalkWalker featuring LexisNexis, download relevant coverage from May 2019 November 2020, Using agreed search string and source list</li> <li>Review of data set to exclude irrelevant mentions from pool of coverage</li> <li>Manual coding of 350 articles, from a representative sample by month and regions</li> <li>Articles coded for:         <ul> <li>Date</li> <li>Journalist</li> <li>Outlet</li> <li>Outlet type</li> <li>Region</li> <li>Original vs. syndication</li> <li>Data use</li> <li>Top 3 narrative strands</li> <li>Top 3 spokespeople</li> <li>Sentiment (Fear, Anger, Optimism, Anticipation, Surprise, Scepticism, Acceptance)</li> </ul> </li> </ul>	<ul> <li>Using TalkWalker and our defined search string, collect all mentions from Twitter</li> <li>Analysis of entire pool of data for key themes of conversation/ hashtags to inform development of bespoke search strings for prominent narrative strands</li> <li>Draft bespoke search strings to isolate specific narrative strands within our coverage</li> <li>Using TalkWalker, identify key influencers (defined by reach, engagement, and shares of content), focusing on organisations/public figures, rather than members of the public</li> <li>Top-line review using in-built demographic information to provide an overview of types of individuals/organisations talking about the topic most frequently</li> </ul>	<ul> <li>Review of peaks in coverage/mentions on social media to identify potential stories to review in more detail</li> <li>Selection of x3 specific examples of health data stories that have generated discourse and engagement on health data</li> <li>Trace the flow from source (e.g. press release, statement) to the media and assess differences in reporting between outlet</li> <li>Using TalkWalker, collect mentions related to a specific story using a bespoke search string and highly limited time frame</li> <li>Using TalkWalker, assess influencers and demographics within key narrative strands from coverage</li> <li>Collation of information flow, tracing how arguments made by specific outlets appear in general public discourse</li> </ul>



MEDIUM	Traditional Media	Social Media
PROS	Extensive coverage reach across a broad range of outlets, including top tier outlets, regional outlets, and broadcast outlets.	High levels of coverage on public social media, with strong ability to analyse the content drawn, the themes covered and types of accounts active in the conversation
CONS	Very small number of local outlets missing  Lower capabilities of deriving readership demographics and in built analysis of themes in long-form articles	Can only access a range of publicly available social media post – so coverage can be dominated by Twitter.  The nature of public conversation on social media can differ from private perceptions – often leaning towards more negative commentary
PROJECT USE	Significant manual coding was conducted to ensure that we are capturing analytical depth from the media  There was clarity on the analysed publications and no major outlet omissions were noted	The public conversation which was most relevant to the brief was taken as the major focus of analysis with an awareness of this limitation  The full extent of the in built analytical capabilities were used to capture insights from the social data



#### Inclusion criteria for content

Articles & posts identified using our search string will be manually assessed to ensure they meet the following criteria:

**Definition** 

Reference to the use of health data as defined by the GDPR (personal and revealing information about an individual's health status), including anonymised data, but not macro-level COVID-19 statistics

**Date range** 

1 May 2019 – 30 November 2020

Region

UK, including discussion of events and stories outside of the UK by outlets and accounts based in the UK

Media

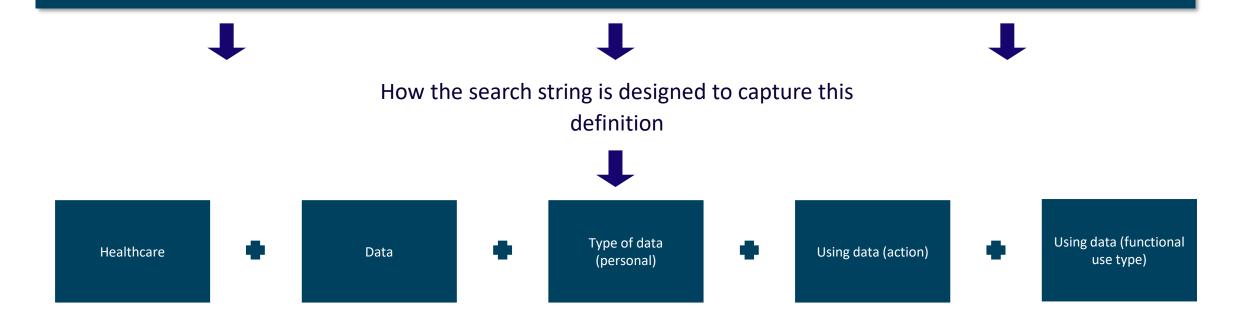
UK traditional print, online and broadcast. Regional print and online. Top tier health trade outlets. Consumer media, including print and online. Excluding aggregators without editorial function.

Social media

UK general public, identified by publicly available location data



**GDPR definition of health data:** 'data concerning health' means personal data related to the physical or mental health of a natural person, including the provision of health care services, which reveal information about his or her health status.





# Search strings: Main search strings

#### Media

((data OR records OR registr\*) SENTENCE (personal OR individual OR patient) AND NOT ("personal protective equipment" NEAR/10 availability)) AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI") AND ((use OR using OR utilised OR utilise OR apply OR application OR access OR breach\* OR leak OR sell\* OR sale OR licens\*) NEAR (passport OR app OR research OR trace OR predict OR treatment OR innovat\* OR plan OR services OR policy OR diagnosis OR confidential OR privacy OR sharing OR "opt-out" OR secure OR safe OR safety OR security OR anonym\* OR improve OR potential OR help OR understand OR recovery OR governance OR genomics OR insurance OR develop\* OR analys\* OR algorithm OR AI OR "artificial intelligence")) AND sourcecountry:uk AND lang:en

#### Social

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND (use\* OR using OR utilis\* OR utilise OR apply OR application OR access OR breach\* OR leak OR sell\* OR sale OR licens\*) AND sourcecountry:uk AND lang:en))



Strand 1: There is a lack of transparency about how this data will be used

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((how OR what) NEAR/6 (use\*))

Strand 2: There
is a lack of
transparency
about who this
data will be
shared with
without consent

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR health CR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((shar\* OR pass\* OR give\* OR transfer OR access) AND (without OR not OR don't OR no) AND (know\* OR consent OR approv\* OR clearance OR acceptance OR authoris\* OR permission OR agree\*))



Strand 3: There is a risk that data will be sold to private companies

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR health CR DR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((private OR corpor\* OR Google OR business OR company OR companies) AND (harvest\* OR sold OR sale OR sell OR bought OR buy OR handover OR given OR trade\* OR market OR commercial OR transfer))

Strand 4: This data should not be being used for advertising/com mercial gains

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((private OR corpor\* OR Google OR business OR apple OR facebook OR google OR amazon OR company OR companies) AND (advert\* OR target OR profit OR benefit OR earnings OR yield))



Strand 5: There
is a need for
greater
regulation
around the use
of personal
health data

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND (regulat\* OR law OR legal\* OR rule) AND NOT ((regulat\* OR law OR legal\* OR rule) Near/4 new)

of security
means that
there is high
potential for
data breaches
or losses

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((breach OR leak\* OR loss OR lost OR "privacy violation" OR vulnerab\* OR insecure OR unsecure OR unsafe OR stolen OR (security AND (lapse OR flaw OR gap OR violation OR problem OR risk OR issue))))



Strand 7: There is a risk that data won't be anonymous

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND (((anonym\*) AND ("isn't" OR "is not" OR "won't be" OR "not")) OR (identifiable))

Strand 8: This data could be used for non-health purposes, e.g. employers, insurance, police/surveillance without consent

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en))

AND (police OR surveillance OR immigration OR employers OR insur\* OR "other purposes" OR profil\* OR advertis\* OR target\* OR marketing) AND NOT ("national insurance number" OR "police records")



Strand 9: There is benefit if data is used to improve an individual's care in the NHS

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((patient OR person OR individual) AND (transform OR improve OR enhance OR strengthen OR boost OR better OR "raise levels" OR "raise standards" OR upgrade OR increase) AND (care OR outcomes OR management OR treatment))

Strand 10: There is benefit if data is used to improve quality of life for a patient population

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND (diagnos\* OR treat\* OR cure\* OR therap\*) AND NOT (covid OR corona)



Strand 11: There is benefit if data is used to make the NHS more efficient

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR health CR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((improve OR enhance OR strengthen OR boost OR better OR "raise levels" OR "raise standards" OR upgrade OR increase OR effic\* OR transform) NEAR/8(NHS OR services OR system OR hospital OR GP))

Strand 12: There is benefit if data is used to improve management of the covid-19 pandemic

((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records))) AND sourcecountry:uk AND lang:en)) AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI") AND ((management OR care OR service OR treatment OR "patient outcomes" OR "patients outcomes" OR outcomes OR control OR manage OR reduce OR understand OR good OR happy OR working OR "no problem" OR "not a problem" OR effective OR important OR vital OR "play a role" OR "play a part" OR "not worried" OR "will download" OR "should download" OR "no issue") NEAR/8 (Covid OR corona\* OR pandemic OR "test and trace" OR Zoe)) AND NOT (concern\* OR seize OR harvest\* OR sold OR sale OR sell OR bought OR buy OR handover OR given OR trade\* OR market OR commercial OR transfer OR "not having my data")



Strand 13: There is benefit if data is used to develop new treatment options for patients

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR health CR DR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((New OR innovat\* OR breakthrough OR option OR results OR trial OR research) NEAR/5 (treatment\* OR therapy OR cure OR remedy OR medicines OR medication\* OR meds OR drug\* OR clinical))

Strand 14: There is benefit if data is use to make things more convenient for people

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR healthcare OR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND (convien\* OR easier OR simplify OR simpler OR "quality of life")



Strand 15: There is a need for people to be more involved in decision-making about the regulation of data

(((((data OR records OR registr\*) SENTENCE (((personal OR individual\* OR patient\* OR anonym\* OR private) NOT ("Private companies" OR "Private company"))) AND ((data OR records OR registr\*) NEAR/3 (personal OR individual\* OR patient\* OR anonym\* OR private))) OR ((my) ONEAR/2 (data OR records OR records)))AND (health OR health CR NHS OR PHE OR "National Health Service" OR "Public Health England" OR "Public health Wales" OR "Department of health and social services" OR "Public Health Scotland" OR "Health and social care Scotland" OR "NHS Scotland" OR "Department of health NI" OR "NI Department of health" OR "HSC Public Health Agency" OR "HSCNI" OR "@PHE\_uk" OR "@PublicHealthW" OR "@DHSCgovuk" OR "@P\_H\_S\_Official" OR "@NHSScotlandCE" OR "@healthdpt" OR "@CommonsHealth" OR "DHSC") AND sourcecountry:uk AND lang:en)) AND ((public OR people OR I OR we) AND (consult OR involv\* OR deci\* OR choose OR choice) AND (regulat\* OR law OR legisl\* OR legal OR rul\*))



#### Glossary of key terms used to code articles around the use of health data

- Routine: Health data collected through routine processes
- COVID-19: Health data collected as a part of the COVID-19 pandemic, or routine data which has been used as a part of the management of the COVID-19 pandemic
- Commercial: Health data which is collected for commercial or marketing purposes
- Clinical research: Health data collected as a part of clinical trials
- Medical research: Health data collected as a part of broader medical research
- Pharmaceutical drug development: Health data collected during the development of pharmaceutical drugs



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For more information, please visit:

- <a href="http://understandingpatientdata.org.uk/">http://understandingpatientdata.org.uk/</a>
- <u>@Patient\_Data</u>