

How data is responding to COVID-19

Thursday 21st May, 2020

The All-Party Parliamentary Group for Data Analytics (APGDA) was delighted to host a remote panel discussion on Thursday 21st May. The discussion brought together a range of sector leaders to look into how data is being used to respond to the on-going COVID-19 pandemic, as well as the challenges for the wider use of medical information across government.

The online roundtable was opened by **Daniel Zeichner MP** at 1500. He began by giving an overview of the pressures facing the country and ways in which data is being used to respond to, and combat the spread of COVID-19 across the country.

The first speaker was Dr Natalie Banner of the [Wellcome Trust](#). She began by providing an overview of the multitude of issues and uses of medical data, both as part of the industry response to COVID-19, as well as across other areas of the economy. The subject is increasingly present in the public eye, and that the present crisis shown by had highlighted the trade-off between protecting public health and the need to protect personal rights and liberties. She noted that the application of data sources is never in a position to be neutral and is always biased by approaches to values and public policy. It would be wrong to be swayed entirely by tech-based solutions. She added that in many areas, medical data was greatly lacking. As an example of this, she noted that a quarter of all medical records did not include ethnicity - a major issue considering the disproportionate impact that COVID-19 is having on BAME individuals. The access and role of technology was also being highlighted as a result of the 'trace and trace' contract app. Public concerns were not entirely focused on notions of privacy and consent - but also around areas such as protecting public safety, as well as the effectiveness. She added the main problem is ensuring that the public maintain their trust in how their information is used. If they do not, there is little buy-in for data use. She concluded by noting how important technology is in looking forward to new threats and opportunities, as well as the Wellcome Trust's recent research into [understanding patient data](#).

The second speaker, Professor [Ross Anderson](#), opened by noting the growing relationship between public bodies and organisations using medical data when they do not have rights to use it. He highlighted the recent crisis at the [Royal Free Hospital with the links with Google DeepMind](#). Professor Anderson criticised the role of Public Health England and the centralised use of medical data by such bodies, in contrast with the old role of local public health boards. The recent introduction of the NHS England tracing app is based on a model developed in Singapore - which he claimed would not work effectively. The aim is to identify epidemiologically relevant individuals - but this has a number of technological issues. Other options are similarly challenged. Tracking individuals using GPS data is not accurate enough, as found out by the Israeli Government. Bluetooth, as an alternative, is also open to

various 'volume' issues and other variables, ranging from where the phone is held to how powerful the phone's bluetooth is. The number of false positives is likely to be highly significant. Even with high quality information and data, the disease's contraction rate of around six percent would also greatly increase the number of false positives available. He followed by noting the problem of false negatives. The Singapore Model found a take-up amongst the population of only 12 percent of the population. The highest penetration for a contact tracing app - Iceland - only had 38 percent take-up. Professor Anderson said that the app - therefore - was a case of 'Do Somethingitis', action is demanded, and doing anything - regardless of effectiveness - is seen by policy makers as a superior option to doing nothing at all. He noted that the proposed track-and-trace app was a medical device classed in the same way as a thermometer and, as such, open to approval before it is used, as well as being noted by an Ethics Committee. The on-going trials of the app on the Isle of Wight had not been formally approved by the usual rules governing the use of the app as a medical device.

The third speaker, [Gavin Freeguard](#) of the [Institute for Government](#), began by explaining how the government was using data more effectively across Whitehall. He highlighted that bodies such as the [Office for National Statistics](#) (ONS) are increasingly using data in more experimental ways, such as seeing if shipping data could be an accurate predictor of GDP. He also said that the role of the data in Government had moved to the [Department for Digital, Culture, Media and Sport](#) (DCMS) in recent years to help formulate the National Data Strategy. One key failure of government has been the inability for Government to have learnt from past mistakes - not least the care.uk scandal. In current times, outside the contract tracing app, government has had to respond rapidly to the COVID-19 crisis, establishing new mechanisms very rapidly, especially the economic models for HM Treasury, and the new furlough and business support being applied by HMRC. Moving forwards - there was also grounds for the government to - in a sense - "rewire the state" to meet the challenges of future pandemics and similar crises. He added that the real issue government would be to decide what their philosophy for the use of data would be.

The final speaker, [Tom Forth](#) of the [Open Data Institute Leeds](#), began by noting a recent conversation he had held with the Dutch Ambassador regarding a new partnership between The Netherlands and the North of England, with a focus on the use of data and technology sharing. He said that the UK had a number of strengths and failures compared with European partners with regard to the public use of data. He singled out the ONS for praise in their use of effective data and statistical sharing, and articulated the effective way in which these were expressed to official bodies, researchers and the public as a whole. Highlighting an example of government failing to use data effectively, he noted the inability for the UK to send out a nationwide text message as part of the COVID-19 response within the parameters of a National Alert System as having contributed to muddled messaging and confusion amongst members of the public. He said it would be invaluable to have a detailed discussion about the systems and processes that made the response to COVID-19 go well, or less so. He said that the French approach to data was highly effective, with regular business and medical data being available within a day on average, compared with the British average of two weeks.

Daniel Zeichner MP then opened the conversation to contributions from the floor.

Maria Burke of the University of Winchester asked the spakers what the UK could learn from France to be more effective in the use of data.

Tom Forth said that this was a challenge as it worked across a range of different areas. With particular reference to the NHS, he said that NHS Digital and NHSx had been late to form such dedicated bodies - but were clearly moving in the right direction. The French approach had also been assisted by the regionalised approach to economic data and information gathering. The decentralisation of power in the French economy was also positive. On a more user-centric approach, one of the downsides of the [GOV.UK](https://www.gov.uk) model consists of a lack of clear accountability for many government services - it is rarely clear which Department is responsible for the use of different data sources, which can help to reduce accountability and public awareness of the subject.

Andrew Cormack of Jisc asked if there were better or more effective ways for Apps to identify COVID-19 hotspots to better inform policy makers.

Ross Anderson said that different countries had different approaches. The Singapore and Greek models involve international visitors to agree to download a track-and-trace app, or otherwise be detained for fourteen days. Such apps would also demand the user to ask permission to leave their area of residence to work properly. He added that such contact and reporting apps could not be effective unless they were designed for specific reasons, rather than responding to all areas of public health.

Tom Forth reiterated this point, noting that successful apps had to be those that did one thing in an effective way. He noted the maxim that the more options an app had, the poorer the way it could be used.

Lord Wallace asked how to get non-experts to contribute to a public debate about the use of data, and how data could be more effectively shared for other users.

Tom Forth noted President Macron's town hall approach around two years ago to gauge public perception of public services. He found that local Mayors and Councillors were far likelier to enjoy a positive relationship and feedback from members of the public, rather than from central government. He also said that a decentralised approach to policy making would - ironically - lead to nationally accepted solutions. The national travel card in The Netherlands came about because of schemes by individual cities and regional transport authorities, with the national government playing almost no role in this.

Jack Tindale added to this, noting that similar principles affected policy making around technology and data in other centralised countries, such as Japan.

Gavin Freeguard said that national discussions had some positive impact in this respect. He said that the Taiwanese Government was engaged in a similar ‘town hall’ approach. He also said that there was merit in discussing data and ethical issues around more tangible ways, such as the use of mobile phone or health data, rather than ethical matters more generally.

Dr Natalie Banner said that ‘data’ itself was not an engaging discussion and - in the experience of the patient data - turned many members of the public away. She said that the Wellcome Trust had found positive responses by focusing on more specific subjects. She added that the idea of a ‘National Conversation On Data’ was also inherently flawed as it led to abstract discussions, rather than specific ideas and concepts. She also found that the [Ada Lovelace Institute](#) had found more complex responses by using more online-focused approaches, rather than simply focusing on survey questions.

Daniel Zeichner asked if the current crisis could lead to a loss of confidence by the public with regard to how their data is used.

Gavin Freeguard said that this should be a major concern by the Government. He noted that the discussions about the use of GOV.UK user data was being discussed largely in private by Cabinet committees. There is still a lack of clarity about how data is shared across various levels of government.

Dr Banner added to this, saying that the current crisis could lead to a situation where action was taken during the crisis, and only discussed earlier. She said that many processes for how data is used already has legal and regulatory frameworks to follow, and that the current approach to COVID-19 was already breaking down these norms.

Christina Phillips of Liverpool John Moores University asked if security risks were increased or decreased as a result of the decentralisation of information.

Ross Anderson said that a decentralised approach to data would gather less data, and would therefore be less effective. However, he said that a contact tracing app was not a private one, given that track and trace is explicitly about identifying individuals. A decentralised approach to data would also make cultural changes in the future harder to implement. He noted that the internet as a whole is too large for adopted technologies to be altered on a whim. He used the example of email being developed thirty years ago, and more secure programmes, such as Signal, had to be developed from the ground-up.

Tom Forth added to this - saying that it would be impossible to develop a nationwide approach to data without a nation-wide database, which also held a number of practical concerns. He gave the example of free bus passes, via smartcard technology, as being a perfect example of how such approaches rarely

work effectively. As an example of this, he noted that the complexities required to make a bus pass in Shetland work on Transport for London service are enormous and are rarely cost-effective

Tom Harrison of the Wellcome Trust highlighted the slow pace at which large bodies can update their technologies and use of data sources - the common perception of the NHS still requiring large numbers of fax machines and pagers is commonly cited. Dr Banner reiterated this, saying that different trusts require a level of intercompatibility across a range of different institutions.

Concluding, Daniel Zeichner thanked attendees for their time, adding that the APGDA would continue to develop policy and public engagement around the use of data in the coming months.

The event ended at 1620.