Royal Statistical Society research on trust in data and attitudes toward data use / data sharing

Introduction

Sharing and analysis of data including 'big data' are growing areas of interest for commercial companies and policymakers. The Royal Statistical Society (RSS) sees real potential benefits from data-sharing, such as improving the quality of statistics, improving evidence for decision-making, and for public benefits, such as finding more effective medical treatments. However there are also public concerns about the use of their data. These are in particular related to privacy issues, as most recently seen in relation to health data ('care.data').

We therefore commissioned this research to get a snapshot of public trust in institutions handling their data, and attitudes toward data linkage and data privacy. In this research, Ipsos MORI polled 2019 GB adults aged 16-75 on the subject of trust in uses of personal data, and data sharing by government bodies.[1] This research is a snapshot of public opinion and should be read alongside more qualitative and deliberative research to build a full picture of public opinion.

Our findings indicate there is a 'data trust deficit' whereby trust in institutions to use data appropriately is lower than trust in them in general. The research also indicates that when a case for public benefit is clearly stated and when there are safeguards in place, more of the public take a positive view in favour of data use and sharing than disagree due to privacy risks. The addition of safeguards such as anonymisation of data, or punishment for data misuse, significantly improves the level of support from 33% to around 51%.[2] It should be noted that this is not to indicate the technical feasibility of anonymisation which is a complex matter and indeed some would argue may not be possible at all depending upon the dataset.

The message for policymakers from our findings is that they need to clearly communicate the value of any data sharing they wish to gain support for, and they need to put safeguards in place. It is also noteworthy that there is considerable opposition to sharing data for commercial purposes, and so this is an area where policy-makers must tread very carefully.

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[1] This was done by an online quota survey of GB adults aged 16-75 using iOnline, Ipsos MORI's online omnibus. Fieldwork for most questions consisted of 2,019 interviews between 23rd and 25th June. One question was placed on a later online omnibus of 1,000 GB adults between 15th to 18th July. Results are weighted by age, gender, region, social grade, working status, main shopper.

[2] 51% is the mean of a four-way split sample with c.505 looking at each safeguard – see p. 7 for chart. For each safeguard we can have 95% confidence that support among the general public would be within +/- 6.5% of what we found.

It should be noted that on some questions the base sample of 2019 adults was split into two groups, and occasionally into three or four. Our published slide deck (available here) includes base numbers for each chart and should be consulted for the number answering any given question. [3]

Findings

A 'data trust deficit'

In general the public does not have a high level of trust in organisations to use their data appropriately. The media, internet companies, telecommunications companies and insurance companies all come at the bottom of a "trust in data" league table. Only between four and seven per cent said that they have a high level of trust in these organisations to use data appropriately, compared with 36% trusting the NHS, and 41% trusting their GP. Nearly all institutions also suffer a "data trust deficit", whereby trust in them to use personal data appropriately is lower than trust generally.

Table 1: Trust to use personal data appropriately, ranked by 'High trust (8-10)'

Q. Please tell me on a score of 0-10 how much you personally trust each of the institutions below to use your personal data appropriately? 0 means you do not trust them at all, and 10 means you have complete trust.		
	High trust (8-10)	**Low trust (0-4)**
Your GP surgery	41%	15%
The NHS	36%	17%
The police	28%	26%
Academic researchers and universities	25%	22%
The Office for National Statistics (ONS)	23%	24%
Charities	15%	35%
Banks	14%	45%
Your local authority	14%	35%
Online retailers, for example, Amazon, Asos and play.com	13%	38%
The British government	13%	46%
Supermarkets	10%	42%
Insurance companies	7%	55%
Telecommunications companies, such as mobile phone companies	6%	54%
Internet companies, such as search engines and social media	6%	54%
The media / the press	4%	68%

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[3] Royal Statistical Society (2014) *Public attitudes to the use and sharing of their data*: *Research for the Royal Statistical Society by Ipsos MORI*. Available from: http://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers (Accessed: July 2014)

Table 2: Low trust in an institution in general vs. low trust to use data appropriately

	Low trust generally (0-4)	Low trust in data (0-4)
Your GP surgery	11%	14%
The NHS	13%	17%
Academic researchers and universities	12%	22%
Charities	21%	35%
Online retailers, for example, Amazon, Asos and play.com	15%	38%
The British government	49%	46%
Supermarkets	23%	42%
Telecommunications companies, such as mobile phone companies	40%	54%
Internet companies, such as search engines and social media	32%	54%
The media / the press	59%	68%

Public worries on data go beyond the "privacy" concern that data may be used to identify them. A substantial minority say that they continue to care about how their data is used, even if there is no way that they personally can be identified from the data.

> "Once my data has been anonymised and there is no way I can be identified, I'm not really bothered how it is used" – 35% disagreed with this statement.

The public shows high support for transparency, as most agreed that they "would really like to know what information government knows about me" (only 5% disagreed). However, the public is unlikely to drive action on transparency by themselves. Only about one in 20 people (5%) said that they have asked a government department, public service or private company what information they hold about them. [4]

On balance, the research suggests there is more support for the government preventing misuse of personal data than there is an appetite to have personal control over this.

> "It's too difficult for me to keep control of all my personal data – it should be the government's job to prevent anyone misusing it." 40% agreed with this, 25% disagreed.

It is hardly surprising that in a fast changing and relatively new regulatory area, there is no clear consensus about whose job it is to deal with issues around personal data.

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[4] In response to: "Have you done any of these things to protect your data or avoid intrusion into your privacy? … Asked a government department, public service or private company what information they hold about you."

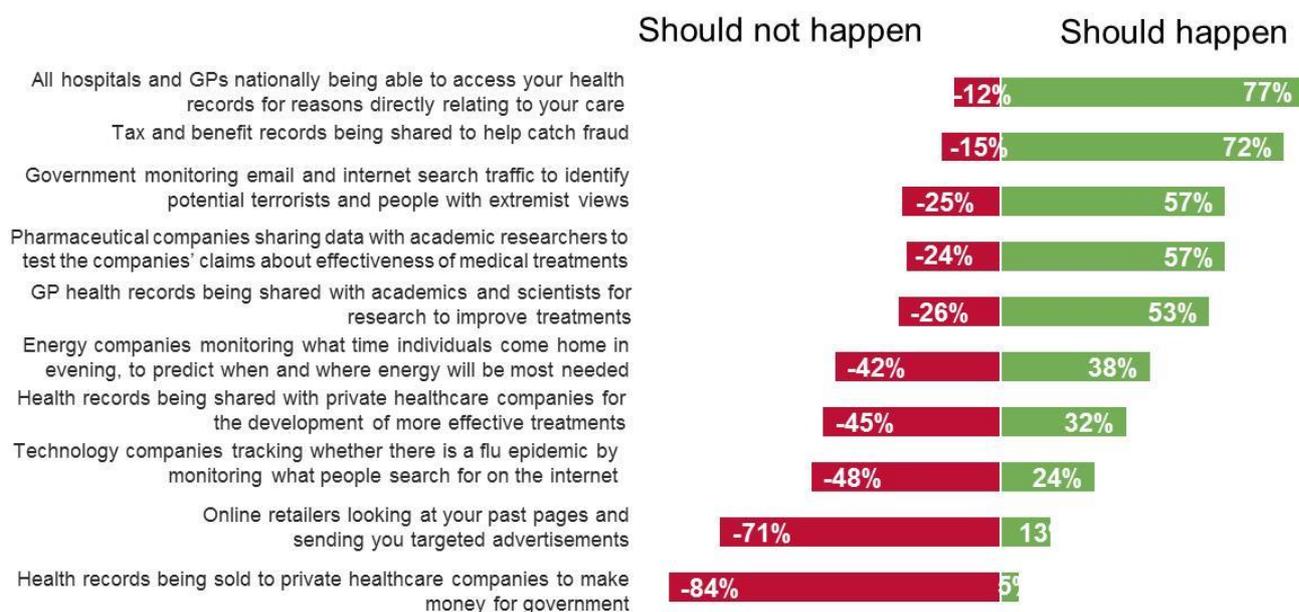**Pragmatic support to use and share data for personal and public benefit**

Prior research has found that support for data to be shared often improves if the context for data sharing is explained and the public is able to deliberate on it. [5] Our findings support this, as they show higher levels of support for data uses in certain contexts.

1. There is more support for data-sharing within government "for the benefit of services and me", with varying safeguards, in comparison to not sharing data at all due to privacy risks. The addition of safeguards such as anonymisation of data, or punishment for data misuse, significantly improves the level of support from 33% to around 51%.[6]

   *When asked to choose between a positive and a negative statement **with the addition of safeguards**, 49-55% were positive (agreeing that we should share all the data we can) and 28-34% were negative (agreeing that we should not share the data due to privacy risks). When asked without any reassurance on safeguards, only 33% chose the positive statement.*

2. When asked about data being used for specific purposes, the public showed highest levels of support for: "all hospitals and GPs nationally being able to access your health records for reasons directly relating to your care (77%), and "tax and benefit records being shared to help catch fraud" (72%).

   Chart 1: "Do you think the following examples should or should not happen?"

Chart 1 data:

	Should not happen	Should happen
All hospitals and GPs nationally being able to access your health records for reasons directly relating to your care	-12%	77%
Tax and benefit records being shared to help catch fraud	-15%	72%
Government monitoring email and internet search traffic to identify potential terrorists and people with extremist views	-25%	57%
Pharmaceutical companies sharing data with academic researchers to test the companies' claims about effectiveness of medical treatments	-24%	57%
GP health records being shared with academics and scientists for research to improve treatments	-26%	53%
Energy companies monitoring what time individuals come home in evening, to predict when and where energy will be most needed	-42%	38%
Health records being shared with private healthcare companies for the development of more effective treatments	-45%	32%
Technology companies tracking whether there is a flu epidemic by monitoring what people search for on the internet	-48%	24%
Online retailers looking at your past pages and sending you targeted advertisements	-71%	13
Health records being sold to private healthcare companies to make money for government	-84%	5

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[5] Economic and Social Research Council (2014). *Public dialogues on using administrative data* [online]. Available from: http://www.esrc.ac.uk/public-engagement/public-dialogues.aspx (Accessed: July 2014)
[6] 51% is the mean of a four-way split sample with c.505 looking at each safeguard. For each safeguard we can have 95% confidence that support among the general public would be within +/- 6.5% of what we found.
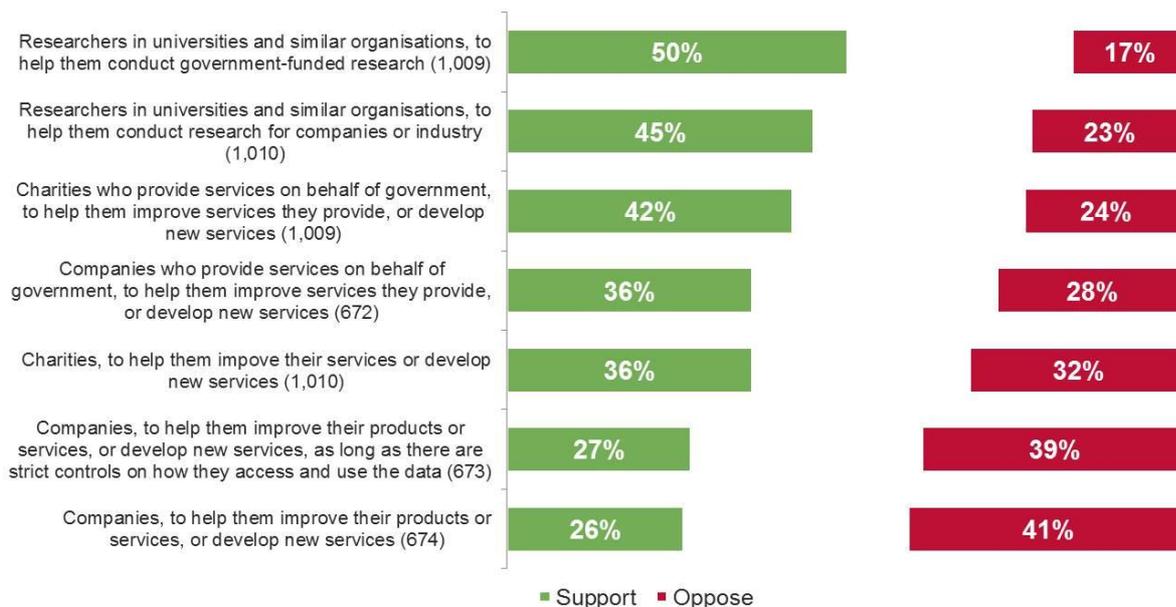
More than half (57%) also support "government monitoring email and internet search traffic to identify potential terrorists and people with extremist views", although 25% opposed this. [7]

3. Interest in public benefit seems also to apply to companies. The majority (57%) supported "pharmaceutical companies sharing their data with academic researchers to test the companies' claims about the effectiveness of medical treatments", while 24% opposed this. However, the public showed very little support for "online retailers looking at your past pages and sending you targeted advertisements", which 71% said should not happen.

A hierarchy of trust – approval of sharing depends on recipient and use

We sought public views on the government sharing anonymised data with third parties outside of government. [8] These are summed up in chart 2, and two key findings are discussed below.

Chart 2: "To what extent, if at all, would you support or oppose government bodies sharing anonymised data with the following organisations?"

Organisation	Support	Oppose
Researchers in universities and similar organisations, to help them conduct government-funded research (1,009)	50%	17%
Researchers in universities and similar organisations, to help them conduct research for companies or industry (1,010)	45%	23%
Charities who provide services on behalf of government, to help them improve services they provide, or develop new services (1,009)	42%	24%
Companies who provide services on behalf of government, to help them improve services they provide, or develop new services (672)	36%	28%
Charities, to help them impove their services or develop new services (1,010)	36%	32%
Companies, to help them improve their products or services, or develop new services, as long as there are strict controls on how they access and use the data (673)	27%	39%
Companies, to help them improve their products or services, or develop new services (674)	26%	41%

■ Support ■ Oppose

1. Support to share data with researchers in universities and similar organisations

The public showed much higher support than opposition for sharing anonymised data with researchers in universities and similar organisations, to help them conduct government-funded research.

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[7] When asked, "do you think the following examples should or should not happen?" Base: 2,019 GB adults 16-75.

[8] We provided the following definition of anonymisation: "When data from public services is being shared, personal data is often anonymised to prevent individuals being identified. This process includes removing identifying information such as a person's name, address and date of birth from the data before sharing."

50% said they would support this (12% strongly support, 38% tend to support), 30% neither support nor oppose, and 17% said they would oppose this (7% strongly oppose, 10% tend to oppose).

Respondents were also quite supportive of researchers using anonymised data to conduct research for companies or industry.

44% said they would support this (9% strongly support, 35% tend to support), 28% neither support nor oppose it, and 23% said they would oppose it (8% strongly oppose, 15% tend to oppose).

2. Opposition to sharing data for companies and charities' own services or commercial interests, which seemed not to reduce by suggesting there will be extra safeguards

More people said they would oppose than would support the government sharing data with "companies, to help them improve their products or services, or develop new services".

41% said they would oppose this (17% strongly oppose, 24% tend to oppose), 29% neither support nor oppose, and 26% said they would support this (5% strongly support, 22% tend to support).[9]

Adding "strict controls on how companies access and use the data" did not significantly reduce opposition. [10]

There was also a fairly low level of support (36%) for government sharing data with charities for charities own interests (to help them improve their services or develop new services).

Respondents were less opposed to sharing data with the private sector when the data goes to "companies who provide services on behalf of government, in order to improve the services they provide…". 28% said they would oppose this.

However public views were more compatible with charities having this role, with support from 42% for this, and opposition from 24%.

In terms of specific uses of data, the greatest opposition was for "health records being sold to private healthcare companies to make money for government" (84%). If records are instead "shared with private healthcare companies to develop more effective treatments", opposition reduces to 45%.[11] (See Chart 1 above, on page 4.)

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[9] Percentages involve some rounding up or down, which is why 26% is not the sum of 5+22.

[10] Statements on companies were tested with a split sample of 674, 673, and 672 for each statement. When asked "to what extent, if at all, would you support or oppose government bodies sharing anonymised data with companies, to help them improve their products or services, or develop new services, as long as there are strict controls on how they access and use the data", 17% said they would strongly oppose, 24% tend to oppose, 29% neither support nor oppose, 24% tend to support, 3% strongly support.
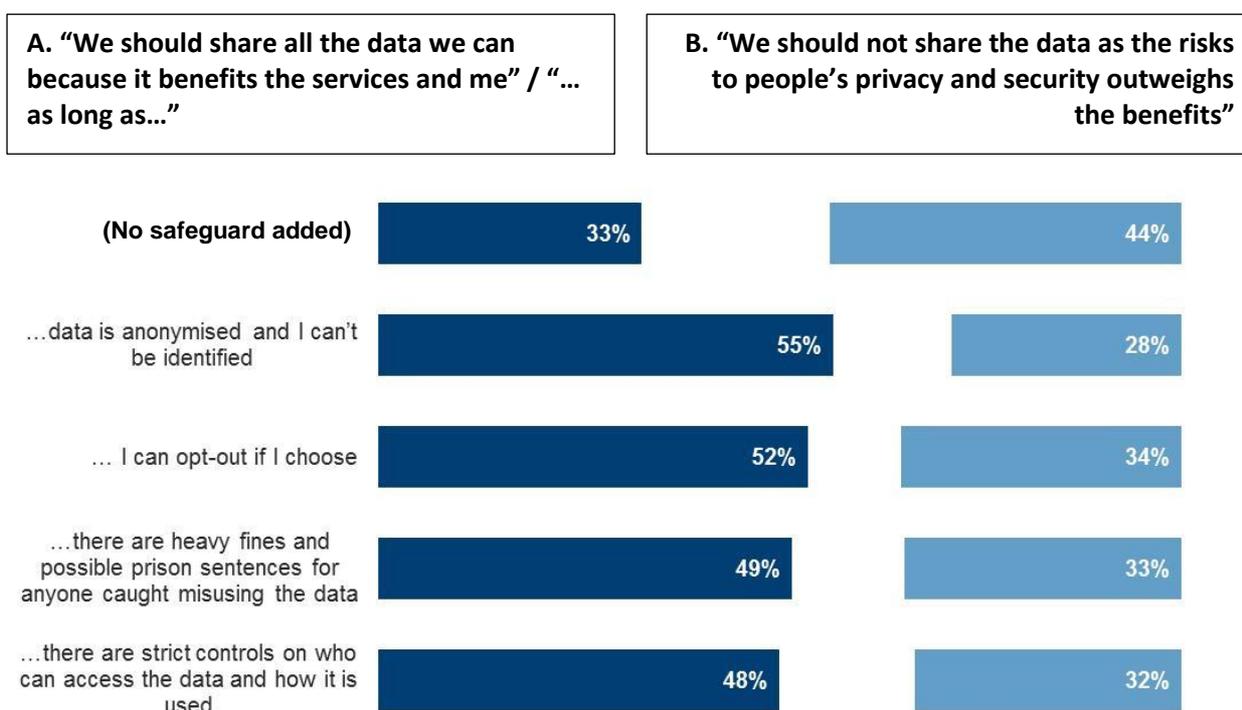
[11] This was tested with a split sample, with 1,010 seeing each statement on private health companies.

Safeguards make a difference

In our question on safeguards, assurance of anonymity attracted the highest level of public support for data sharing, at 55% (see Chart 3 below). Providing people an 'opt out', harsh penalties on data misuse, and controls on data access all also made a difference. We used a split sample on this question, so that those responding to one safeguard did not see other safeguarding options. Due to the likely variance from this smaller sample size, we can't say with confidence that the same ranking of safeguards would apply among the public as a whole. [12] What we can say however is that each of the given safeguards made a difference, in comparison to making no mention of safeguards at all.

Chart 3: "Overall, which of the following statements is closest to your view?"

	A. "We should share all the data we can because it benefits the services and me" / "… as long as…"	B. "We should not share the data as the risks to people's privacy and security outweighs the benefits"
(No safeguard added)	33%	44%
…data is anonymised and I can't be identified	55%	28%
… I can opt-out if I choose	52%	34%
…there are heavy fines and possible prison sentences for anyone caught misusing the data	49%	33%
…there are strict controls on who can access the data and how it is used	48%	32%

Methods and limitations

The public views gathered here inevitably reflect immediate reactions based on partial understanding. They are no substitute for open consultation on specific proposals or changes which the government or a company might make. For example, across many questions approximately one third of respondents gave neither one view nor the other. This may not reflect apathy but rather lack of confidence or interest to express a view. The poll was also conducted online which may differ from telephone or interview findings. Our research findings should also

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[12] For each safeguard we can have 95% confidence that support among the general public would be within +/- 6.5% of what we have found.

ideally be read alongside qualitative findings, such as findings from public workshops conducted with smaller numbers of participants. [13] What we have found however is in keeping with and builds upon findings from other recent polls and research, of which Sciencewise has produced a summary review. [14]

In the slides' appendix, Ipsos MORI provides a note on statistical significance and the extent to which findings can be assumed to apply among the general public. The expected variance depends on the sample size. Generally speaking, where a question is asked to all 2019 participants, the difference in our results compared to what would come from the general public is expected to be in the region of +/- 2.2% at most. [15]

Further information

If you have any questions on this briefing note please contact Olivia Varley-Winter (o.varley-winter@rss.org.uk). If you would like to work with us on this agenda please contact our Executive Director, Hetan Shah (h.shah@rss.org.uk).

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[13] Economic and Social Research Council (2014). *Public dialogues on using administrative data* [online]. Available from: http://www.esrc.ac.uk/public-engagement/public-dialogues.aspx (Accessed: July 2014)

[14] Sciencewise expert resource centre (2014). *Big Data: Public views on the collection, sharing and use of personal data by government and companies* [pdf]. Available from: http://www.sciencewise-erc.org.uk/cms/assets/Uploads/SocialIntelligenceBigData.pdf (Accessed: July 2014)

[15] Slide 42 in Royal Statistical Society (2014) *Public attitudes to the use and sharing of their data*: *Research for the Royal Statistical Society by Ipsos MORI*. Available from: http://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers (Accessed: July 2014)