



Trust, Security and Public Interest: Striking the Balance

*A review of previous literature on public attitudes towards the sharing
and linking of administrative data for research*

Executive Summary

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Executive Summary

This literature review explores previous research into the UK public's attitudes towards the linking and use of administrative data for research, and the conditions under which it is felt it should and should not happen.

In recent years, a large amount of public consultation and attitudinal work has been conducted in relation to the collection and use of data, as well as specifically in relation to the linking and use of administrative data for research. This review of previous work finds that the public is broadly supportive of the use of administrative data for research, as long as three core conditions are met:

1. **Public interest** – any research using administrative data must demonstrate that it is in the public interest and has potential to lead to tangible benefits for society;
2. **Privacy and security** – data being linked and used for research must be de-identified, and protections must be in place to prevent it from being re-identified or misused;
3. **Trust and transparency** – trust in those holding and using data is paramount; and transparency around how data is held and used is essential.

None of these three conditions is sufficient in isolation; rather, the literature shows that the public's support for the use of administrative data for research is underpinned by a minimum standard of all three. The literature also shows, however, that in certain cases where the standard of one condition is very high – for example, public interest – this could mean that of another – for example, privacy and security – may, if necessary, be lower. An appropriate balance must be struck, and the proposed benefit must outweigh the potential risk. Nevertheless, certain minimum standards are expected in all situations to secure public support.

Three core conditions of public support for sharing administrative data for research



Public interest

Research using administrative data must be in the public interest and demonstrate real potential for public good.



Privacy and security

Data shared for research must be de-identified, with protections in place to prevent it from re-identification or misuse.



Trust and transparency

Trust in those holding and using data is paramount; and transparency around how data is held and used is essential.

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This review shows that broad, conditional support for the use of administrative data in research has not only been found consistently, but has also been held over time, with data collection for the studies included spanning more than a decade from 2006-2018.

In light of this, it is now appropriate to move beyond widescale, general consultation on the use of administrative data for research and instead build upon existing knowledge by delving into specific areas of research. This could involve engaging with sub-sectors of society relevant to these areas, or with a cross-section of society on a particular aspect of the use of administrative data. This enables a greater focus on the issues important to the people whose lives may be directly affected by research conducted using their data, in a more specific context. **The purpose of such an approach would not be to consult on whether research using administrative data *should* be done – as has been the focus of previous literature – but rather to guide *how, why* and *when* it is done.** Nevertheless, it is important to continue to monitor and respond to any changes to public attitudes and adapt approaches if necessary.

The [full review](#) sets out the findings of previous research and finishes by setting out the details of ADR UK's approach in light of these.



The ADR UK Approach

Previous literature has shed light upon the public's attitudes towards the use of administrative data for research. This review shows that the public are broadly in favour of administrative data research, as long as certain conditions are met.

Ultimately, the proposed benefit must outweigh the potential risk, and this is dependent upon the specifics of any given project, including: the data being used; the questions being asked; the protections in place; and the institutions or individuals accessing the data. These attitudes have been shown to have been held over time, in work done both over a decade ago and more recently, with this review covering studies conducted between 2006-2018. Nevertheless, it is important to note that the nature of research is such that it is not always possible to know if it will ultimately prove beneficial. The findings are not known at the start, and all we can aim for is intended benefit.

ADR UK's structure and approach ensures that each of the three conditions underpinning public support for research using administrative data as identified in this review are at the core of everything we do:

1. Public interest

All research which hopes to use data curated by ADR UK must submit a research proposal that demonstrates robust methodology and public interest. 'Public interest' is assessed as per the definition set out in the *Research Code of Practice and Accreditation Criteria* under Part 5 of the 2017 Digital Economy Act (DEA), which was established on the basis of public consultation. According to the Code, 'research in the public interest' is:

*"...research whose primary purpose is, for example, to: i) provide an evidence base for public policy decision-making; ii) provide an evidence base for public service delivery; iii) provide an evidence base for decisions which are likely to significantly benefit the economy, society or quality of life of people in the UK, UK nationals or people born in the UK now living abroad; iv) replicate, validate, challenge or review existing research and proposed research publications, including official statistics; v) significantly extend understanding of social or economic trends or events by improving knowledge or challenging widely accepted analyses; and/or, vi) improve the quality, coverage or presentation of existing research, including official or National Statistics."*¹

ADR UK-curated data is only made available to approved researchers for projects which can demonstrate public interest in line with this definition. This review has found no reason to challenge or seek change to the implementation of this definition in the context of administrative data research. However, as discussed above, there is no widely understood definition of 'public interest' amongst the public. Understanding what the benefits of administrative data research are considered to be by the communities the work aims to benefit therefore remains an important goal of public engagement.

2. Privacy and security

Improving lives is at the core of ADR UK's mission and the secure handling of data underpins this. Data shared with researchers via ADR UK is de-identified: when accessible to

¹ Digital Economy Act 2017 Part 5: Codes of Practice, ['Research Codes of Practice and Accreditation Criteria'](#), Principle 4: Public interest (accessed 17/04/20)

researchers, it does not include any personal identifiers, with any elements that could be traced directly back to individuals – such as names and addresses – having been removed. Only the sub-sets of de-identified datasets – the variables needed by researchers to answer their specific research questions – are made available for use.

ADR UK partners have rigorous measures in place to ensure data cannot be accessed by any unauthorised persons, and operate according to the ‘Five Safes’ – a set of established safeguards to ensure data is kept safe and secure: Safe data, Safe person, Safe project, Safe place, and Safe output². Once researchers have been vetted and approved, they must access data via a secure physical research facility – or a secure connection to one – provided by an ADR UK partner. Researcher activity is closely monitored and outputs are checked before being released to ensure data has not been misused in any way. Data made available to researchers by ADR UK is therefore anonymous as per the definition set out by the Information Commissioners Office (2012), which states that anonymised data is data “*in a form that does not identify individuals and where identification through its combination with other data is not likely to take place*”³.

3. Trust and transparency

ADR UK is a publicly-funded, apolitical body. The academic research that ADR UK facilitates is driven by a desire to understand and improve society, rather than to advance specific agendas. Researchers wishing to use data curated by ADR UK must go through a rigorous approval process. They must be an approved researcher with the necessary qualifications and expertise to carry out the proposed research, and must have a research project with robust methodology that has been approved as being in the public interest.

We are committed to transparency and effective communication, and strive to ensure the public is kept well informed about our work via up-to-date digital communications, public events and more. We work hard to do this in a way that is understandable and accessible to a variety of audiences, using text, video, infographics and more.

² Office for National Statistics (2017), [‘The ‘Five Safes’ – Data Privacy at ONS’ \(accessed 17/04/20\)](#)

³ Information Commissioner’s Office (2012), [‘Anonymisation: Managing data protection risk code of practice’](#), p.48.

Public engagement with ADR UK

In light of the findings of this review, and due to the volume of existing literature and the consistent findings it has had, ADR UK will move beyond widespread, general consultation about the uses of administrative data for research. We will now hone in on the more specific work underway to build upon – and not repeat – existing work. This will bring to life the research that has as of yet mostly been shown to the public in an abstract sense, and seek their engagement with specific research programmes. This will involve engaging with the demographics and communities to whom each of our projects is relevant and whose lives are impacted by the work – both directly and via relevant community representatives, for example charities and community groups. This is also in line with UK Research & Innovation’s ‘Vision for Public Engagement’ (2019), which sets out ambitions to “engage under-represented communities and places with research and innovation”, “actively involve a wide range of people in their work” and “listen to public concerns and aspirations”. We will continue to monitor any changes to public attitudes identified by other, broader attitudinal work, and adapt our approach where necessary.

Previous literature has provided valuable insights into public attitudes towards the linkage and use of administrative data for research and set out a clear route forwards for ADR UK’s own public engagement. You can find out more about ADR UK’s approach to enabling better access to linked administrative data for research, and keep up-to-date with our public engagement activities as they unfold, on the [ADR UK website](#).

You can access the [full literature review](#) on the ADR UK website.

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