


RESEARCH ARTICLE

Emerging health data platforms: From individual control to collective data governance

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Received: 19 December 2019; **Revised:** 23 June 2020; **Accepted:** 12 July 2020

Keywords: data governance; data stewardship; emerging data platforms; health data; person generated health data

Abbreviations: EHR, Electronic Health Records; EU, European Union; GDPR, General Data Protection Regulation; HRB, Health Record Bank; ODI, Open Data Institute; PLM, Patients Like Me

Abstract

Abstracts should be 250 words. It must be able to stand alone and so cannot contain citations to the paper's references, equations, etc. An abstract must consist of a single paragraph and be concise. Because of online formatting, abstracts must appear as plain as possible.

Policy Significance Statement

Provide a 120 word statement here that summarises the significance of the work for policymakers, written at a level understandable for a broad audience.

1. Introduction

The introduction introduces the context and summarizes the manuscript. It is important to clearly state the contributions of this piece of work. The potential offered to policy makers by data-driven research is greater than it ever has been. Increasing volumes of data, faster technology, and evolving techniques and methodology enable us to process ever more data faster, providing the opportunity to focus and evaluate policies to deliver more effectively and economically at a time when efficient use of public money is paramount.

More data can now be analyzed faster enabling researchers to explore more and more complex interactions. Data across a wide spectrum from open data¹ that can be downloaded, through licensed data,² to sensitive personal data can now contribute to our understanding of health, social, and economic outcomes.

The United Kingdom has a long tradition of safe data use by researchers. In the 50 years that the UK Data Archive has been making data available for social and economic research, there have been

¹<https://data.gov.uk/>

²<https://www.ukdataservice.ac.uk/>

no damaging disclosures of personal information by academic researchers³. While increasing use of detailed and sometimes sensitive data can contribute valuable insights for targeting policies, we cannot be complacent. In order to support our policy needs and continue to use data safely and effectively, we need a research infrastructure that protects data confidentiality while enabling researchers to undertake innovative research.

A first step toward protecting sensitive data is to keep control of it, to disseminate access, not data. Data providers internationally are increasing, moving toward systems in which researchers remotely access and analyses data that are stored within a controlled environment, with any data that are removed from the system being checked in some way to minimize chances of disclosure.

This paper will look at remote data access as one method of protecting sensitive data while enabling its effective use for research. It will look at how the Digital Economy Act can strengthen the UK data research infrastructure and make some recommendations for other improvements

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³That is not to say that there have been no breaches—researchers using data for a project they are not licensed for or passing data to unlicensed colleagues—however, this, as far as we are aware of, has never caused harm to individuals or entities in the data.

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Once data are disseminated, whatever contractual or other obligations are placed on those receiving the data, the data are effectively out of a data providers' control. Data providers must be certain that the data disseminated do not provide a risk of disclosure necessitating a reduction in the detail available, or they are constrained to using a resource intensive auditing regime, and are likely to discover any data misuse only after it has happened.

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⁴Though this facility is used in the Netherlands for secure access to government data, it does not currently exist in the UK for any government data access as far as the author is aware.

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4. Equations

Equations in \LaTeX can either be inline or on-a-line by itself. For inline equations use the $\$ \dots \$$ commands. Eg: The equation $H\psi = E\psi$ is written via the command $H\psi = E\psi$.

For on-a-line by itself equations (with auto generated equation numbers) one can use the equation or eqnarray environments D .

$$\mathcal{L} = i\psi\gamma^\mu D_\mu\psi - \frac{1}{4}F_{\mu\nu}^a F^{a\mu\nu} - m\psi\psi \quad (1)$$

where,

$$\begin{aligned} D_\mu &= \partial_\mu - ig\frac{\lambda^a}{2}A_\mu^a \\ F_{\mu\nu}^a &= \partial_\mu A_\nu^a - \partial_\nu A_\mu^a + gf^{abc}A_\mu^b A_\nu^a \end{aligned} \quad (2)$$

Notice the use of `\nonumber` in the align environment at the end of each line, except the last, so as not to produce equation numbers on lines where no equation numbers are required. The `\label{ }` command should only be used at the last line of an align environment where `\nonumber` is not used.

$$Y_\infty = \left(\frac{m}{\text{GeV}}\right)^{-3} \left[1 + \frac{3 \ln(m/\text{GeV})}{15} + \frac{\ln(c_2/5)}{15} \right] \quad (3)$$

The class file also supports the use of `\mathbb{R}`, `\mathscr{R}` and `\mathcal{R}` commands. As such `\mathbb{R}`, `\mathscr{R}` and `\mathcal{R}` produces \mathbb{R} , \mathscr{R} and \mathcal{R} respectively.

5. Tables

Tables can be inserted via the normal table and tabular environment. To put footnotes inside tables one has to use the additional “fntable” environment enclosing the tabular environment. The footnote appears just below the table itself.

6. Figures

As per the \LaTeX standards eps images in latex and pdf/jpg/png images in pdflatex should be used. This is one of the major differences between latex and pdflatex. The images should be single page documents. The command for inserting images for latex and pdflatex can be generalized. The package that should be used is the graphicx package.



Figure 1. This is a widefig. This is an example of long caption this is an example of long caption this is an example of long caption this is an example of long caption.

7. Cross referencing

Environments such as figure, table, equation, align can have a label declared via the `\label{#label}` command. For figures and table environments one should use the `\label{}` command inside or just below the `\caption{}` command. One can then use the `\ref{#label}` command to cross-reference them. As an example, consider the label declared for Figure 1 which is `\label{fig1}`. To cross-reference it, use the command `Figure \ref{fig1}`, for which it comes up as “Figure 1”. The reference citations should used as per the "natbib" packages. Some sample citations: [Herbst-Damm and Kulik \(2005\)](#); [Gilbert et al. \(2004\)](#); [Light and Light \(2008\)](#); [Shotton \(1989\)](#); [Schiraldi \(2001\)](#); [VandenBos \(2007\)](#); [Freud \(1953\)](#).

8. Lists

List in \LaTeX can be of three types: enumerate, itemize and description. In each environments, new entry is added via the `\item` command. Enumerate creates numbered lists, itemize creates bulleted lists and description creates description lists. List in \LaTeX can be of three types: enumerate, itemize and description. In each environments, new entry is added via the `\item` command. Enumerate creates numbered lists, itemize creates bulleted lists and description creates description lists.

1. This is the 1st item
2. Enumerate creates numbered lists, itemize creates bulleted lists and description creates description lists.
3. Numbered lists continue.

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- This is the 1st item
- Itemize creates bulleted lists and description creates description lists.
- Bullet lists continue.

Table 1. Tables which are too long to fit, should be written using the “table*” environment as shown here Tables which are too long to fit, should be written using the “table*” environment as shown here

Projectile	Element 1			Element 2 ¹		
	Energy	σ_{calc}	σ_{expt}	Energy	σ_{calc}	σ_{expt}
Element 3	990 A	1168	1547 ± 12	780 A	1166	1239 ± 100
Element 4	500 A	961	922 ± 10	900 A	1268	1092 ± 40

Note: This is an example of table footnote this is an example of table footnote this is an example of table footnote this is an example of table footnote this is an example of table footnote
¹This is an example of table footnote

9. Conclusion

Some Conclusions here.

Acknowledgments. We are grateful for the technical assistance of A. Author.

Funding Statement. This research was supported by grants from the <funder-name><doi>(<award ID>); <funder-name><doi>(<award ID>).

Competing Interests. A statement about any financial, professional, contractual or personal relationships or situations that could be perceived to impact the presentation of the work — or ‘None’ if none exist

Data Availability Statement. A statement about how to access data, code and other materials allowing users to understand, verify and replicate findings — e.g. Replication data and code can be found in Harvard Dataverse: <https://doi.org/link>.

Ethical Standards. The research meets all ethical guidelines, including adherence to the legal requirements of the study country.

Author Contributions. A.A. and A.B.C. designed the study, abstracted the data wrote the first draft, and approved the final version of the manuscript. A.R.E.J., M.R.L., K.L.S., and A.D.P. revised the manuscript and approved the final version.

Supplementary Material. State whether any supplementary material intended for publication has been provided with the submission.

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