Understanding Longitudinal Population Study Data and the Law

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Background

UK Longitudinal Linkage Collaboration (UK LLC) is the national Trusted Research Environment for the UK's longitudinal studies. The need for a clear way to communicate Longitudinal Population Study (LPS) participants' rights was identified through public contributor consultations. UK LLC gathered public views to inform meaningful discussion with NHS England, the National Data Guardian's Office, and the Health Research Authority to develop a new framework for agreeing consistency in assessment of the legal basis for linking participant self-reported data to participants' health records. The consultation flagged that the legislation around LPS data is complex, confusing, and often inaccessible. This means that it may prove difficult for LPS participants to fully understand who is allowed to access their data, for what purposes, under what circumstances and what their rights are.

Introduction

The legal basis for using LPS data is complex. Of particular importance are the UK GDPR (General Data Protection Regulations), Common Law Duty of Confidentiality, Digital Economy Act (DEA) 2017 and Section 251 of the NHS Act 2016. Our vision was to produce transparency materials to help LPS participants understand LPS data and the law.

Methods

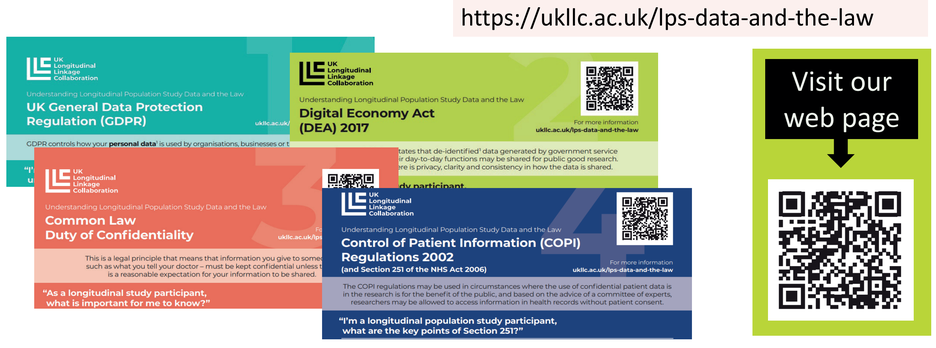
1. **We surveyed public contributors** from UK LLC, Health Data Research UK and DATAMIND to establish current understanding.
2. **We worked in partnership** with UK LLC's Public Advisory Group (PAG) and external organisations to produce a series of infographics (also available in audio, BSL and additional languages) to reach as wide an audience as possible.
3. **We collaborated** with DATAMIND throughout the project sharing insights and ideas.

Outputs

UK Health Data Research Alliance Transparency Standard No.4: consider target audience: *website should use appropriate language for the audience and should include content specifically developed for members of the public in readily understandable terms.*

UK LLC's website features the infographic series. Over time, this will be expanded to include a set of accessibility materials to broaden the range of people who can engage with the content. This includes an audio version, British Sign Language videos and language translations.

https://ukllc.ac.uk/lps-data-and-the-law



Lessons learnt

This work demonstrated that understanding how to interpret the laws and legal principles related to the use of data are complex. Often during discussions across organisations there was a range of views on the optimum way to communicate the key messages in lay language.

While there has been extensive discussion with people from several organisations, the priority was to take the lead from the public contributors on language, format and levels of detail.

Results

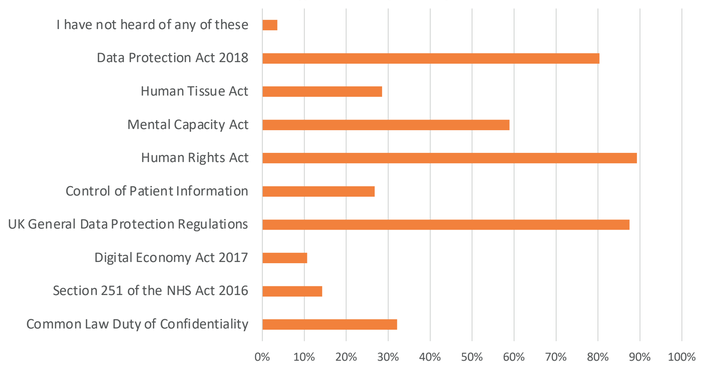
A total of 56 people participated in the survey, most of whom lived in England: 30% were LPS participants; 55% were aged 55 and over; and 18% identified as belonging to an ethnic minority group. Survey results showed that the levels of awareness of the laws/legal principles relating to the use of LPS data is generally low. The DEA was least well-known, with 11% of people aware of this legislation. The most well-known of the infographic topics was GDPR, with 88% awareness.

We co-developed key messages for LPS participants on what they should be aware of as individuals, including what they should expect from their LPS. This was not a straightforward process due to the exemptions and conditions under each law/legal principle. This led to focus on highlighting the practical implications for participants rather than explaining the laws/legal principles. Across the series, participants are directed to official organisations for further information.

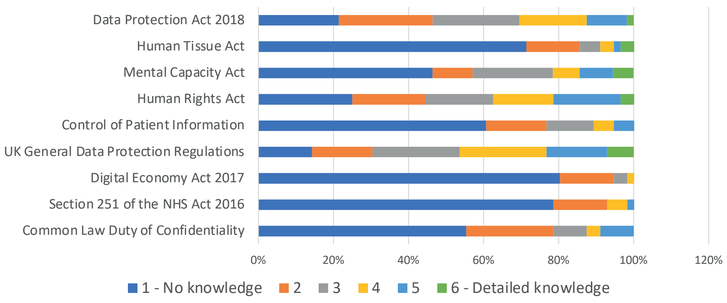
Survey selection: seeking levels of understanding across the laws and legal principles

We asked a total of 35 questions on a variety of topics related to the use of participant data. We sought to understand people's awareness and knowledge levels of a range of laws/legal principles, including the topics selected for the infographic series and whether or not they were aware of the various circumstances under which their data may be used. Questions included awareness and preferences around opt-in/opt-out mechanisms.

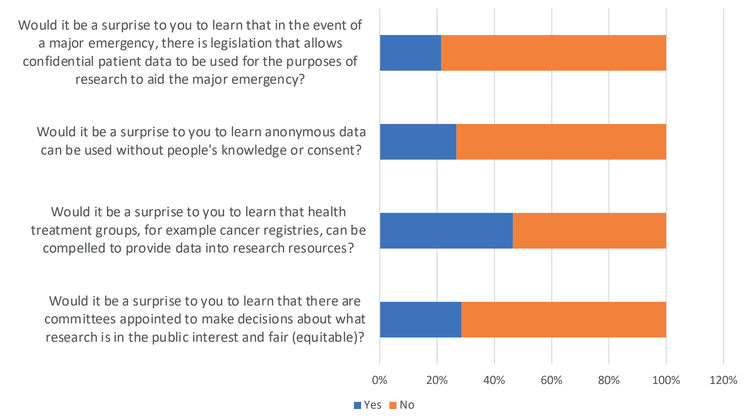
Have you heard of any of the following laws and safeguards? (n=56)



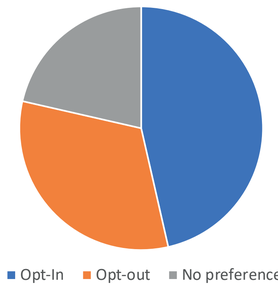
Out of a score of 6 (where 1 is no knowledge and 6 is detailed knowledge) where would you say your level of knowledge sits on each area of laws and safeguards? (n=56)



General awareness of circumstances of data use (n=56)



Individuals have the right to choose whether their personal data is used in research, does it matter to you if this was done through an opt-in or opt-out mechanism? (n=56)



Conclusions & Impact

This series of transparency materials provides a more accessible and easy-to-understand way for LPS participants to fully understand who is allowed to access their data, for what purposes, under what circumstances and what their rights are. The intended impact is for participants to be more fully informed, understanding the practical implications in relation to the use of their data, and to raise awareness and understanding for members of the public through the onward sharing of these materials.

Acknowledgements

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