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Understanding Longitudinal Population Study Data and the Law

Kirsteen Campbell¹, Rebecca Whitehorn¹, Sarah Chave², Michael Gregg², Mhairi Docherty², Rosie Hill², Emma Turner³, Katharine Evans³, Jacqui Oakley³, Robin Flaig¹, and Andy Boyd³

¹University of Edinburgh

²UK LLC Public Advisory Group

³University of Bristol

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

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

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 among 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.

Conclusions

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.

