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The other side of the coin: harm due to the non-use of health-related data

Jones, Kerina^{1*}, Laurie, Graeme², Stevens, Leslie², Dobbs, Christine¹, and Ford, David¹

¹Swansea University
²University of Edinburgh
³University College London

Objectives

It is widely acknowledged that breaches and misuses of healthrelated data can have serious implications and consequently they often carry penalties. However, harm due to the omission of health data usage, or data non use, is a subject that lacks attention. A better understanding of this other side of the coin is required before it can be addressed effectively.

Approach

This article uses an international case study approach to explore why data non use is difficult to ascertain, the sources and types of health-related data non-use, its implications for citizens and society and some of the reasons it occurs. It does this by focussing on issues with clinical care records, research data and governance frameworks and associated examples of non-use.

Results

The non-use of health-related data is a complex issue with multiple sources and reasons contributing to it. Instances of data non-use can be associated with harm, but taken together they describe a trail of data non-use, and this may complicate and compound its impacts. Actual evidence of data non-use is sparse and harm due to data non use is difficult to prove. But although it can be nebulous, it is a real problem with largely unquantifiable consequences. There is ample indirect evidence that health data non-use is implicated in the deaths of many thousands of people and potentially £billions in financial burdens to societies.

Conclusion

The most effective initiatives to address specific contexts of data non-use will be those that are cognisant of the multiple aspects

*Corresponding Author: Email Address: k.h.jones@swansea.ac.uk (K. Jones) to this complex issue, in order to move towards socially responsible reuse of data becoming the norm to save lives and resources.



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