



Swansea University
Prifysgol Abertawe



Cronfa - Swansea University Open Access Repository

This is an author produced version of a paper published in:
International Journal for Population Data Science

Cronfa URL for this paper:
<http://cronfa.swan.ac.uk/Record/cronfa34916>

Paper:

Lea, N., Ford, D., Dobbs, C., Stevens, L., Laurie, G. & Jones, K. (2017). The other side of the coin: harm due to the non-use of health-related data. *International Journal for Population Data Science*, 1(1)
<http://dx.doi.org/10.23889/ijpds.v1i1.52>

This work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.

This item is brought to you by Swansea University. Any person downloading material is agreeing to abide by the terms of the repository licence. Copies of full text items may be used or reproduced in any format or medium, without prior permission for personal research or study, educational or non-commercial purposes only. The copyright for any work remains with the original author unless otherwise specified. The full-text must not be sold in any format or medium without the formal permission of the copyright holder.

Permission for multiple reproductions should be obtained from the original author.

Authors are personally responsible for adhering to copyright and publisher restrictions when uploading content to the repository.

<http://www.swansea.ac.uk/iss/researchsupport/cronfa-support/>

International Journal of Population Data Science



Swansea University
Prifysgol Abertawe

Journal Website: www.ijpds.org

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 health-related 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.

to this complex issue, in order to move towards socially responsible reuse of data becoming the norm to save lives and resources.

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)

<http://dx.doi.org/10.23889/ijpds.v1i1.52>

August 2016 © The Authors. Open Access under CC BY-NC-ND 4.0 (<https://creativecommons.org/licenses/by-nc-nd/4.0/deed.en>)

