



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



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ABSTRACT

Introduction: 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.

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 and discussion: The non-use of health-related data is a complex issue with multiple explanations. Individual instances of data non-use can be associated with harm, but taken together, they can describe a trail of data non-use that may complicate and compound its impacts. 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.

Conclusions: Harm due to the non-use of health data is difficult to attribute unequivocally and actual proven evidence is sparse. Although it can be elusive, it is nevertheless a real problem with widespread and serious, if largely unquantifiable, consequences. The most effective initiatives to address specific contexts of data non-use will be those that: firstly, understand the pertinent sources, types and reasons for data non-use in a given domain in order to meet the challenges and create appropriate incentives and repercussions; and secondly, are cognisant of the multiple aspects to this complex issue in other domains to keep benefits and limitations in perspective, to move steadily towards socially responsible reuse of data becoming the norm to save lives and resources.

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1. Introduction

In 2014, the (UK) Nuffield Council on Bioethics Working Party on Biological and Health Data and the Wellcome Trust's Expert Advisory Group on Data Access commissioned a review of evidence relating to harm resulting from uses of health and biomedical data [1]. The main focus was on harms resulting from data uses, but harms due to omission of data usage (or non-use of data) were also considered. The review took a multi-faceted approach, using hard and soft evidence strands from legal sources, the grey literature

and social media, and merging the evidence for analysis [1]. However, little/no actual evidence of harm due to the non-use of data was revealed by the searches used in the review, except that two cases concerning interference in human rights were uncovered in the legal strand. One focussed on a request for access to children's health data and the other on the non-disclosure of data on exposure to radiation on Christmas Island in 1958 [1]. This lack of evidence was no real surprise because the searches were focussed on finding proven cases of harm, and it would be challenging at best to determine with a high degree of confidence whether an instance of harm was truly due to the non-use of data, or if its causes were otherwise.

It is commonly acknowledged that health-related data routinely collected as part of everyday practice, or generated as part of a

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research study, have great potential to improve patient care, citizens' lives and professional services. However, this potential is often thwarted by data non-use. There is much publicity about data losses and misuses of data, but what about the other side of the coin – harms due to the non-use of health-related data? There is a lack of evidence about the reasons these data are not being used, an associated lack of appreciation of the harms arising from their non-use, and little indication of the scale of the problem. Therefore, this paper focusses on the non-use of health-related data. It sets out to identify and discuss some important types of data non-use to help clarify why harms due to this issue are not more evident. By using international case study examples it will illustrate the types of problem that can arise through the non-use of health-related data and the implications of this for citizens and society. It will touch upon some of the current initiatives to address data non-use, and by exploring the apparent reasons for non-use, will highlight the remaining challenges for effective data use.

2. Approach

A crucial part of the approach used in this article is to focus on harm due to the non-use of health-related data, as distinct from the benefits due to proper data usage. This is because it would be inaccurate to invert the latter and effectively equate the two. That is, it could be dangerously misleading to postulate that benefits resulting from the use of data would not have been realised, and that the opposite outcomes would have occurred, if those data had not been used. Whilst the complexities and constraints of the legislative and regulatory governance frameworks are undoubtedly relevant here, some other, rather fundamental, factors are at play in the non-use of data. Using a case study approach, issues with clinical care records and research data will be considered before moving on to governance frameworks. This will illustrate sources and types of non-use, their implications, possible reasons they occur and challenges to be addressed. It is appreciated that clinicians, researchers and governance professionals will have an awareness of issues, particularly within their own domains, but one of the novel aspects of this study is to consider a more holistic view of data non-use and its impacts. This is the first known study to address the topic of health-related data non-use in this way. The article is written from a UK standpoint, but this is a global issue, and therefore includes international case studies.

3. Results and discussion

3.1. Clinical records

In 1995, the UK National Audit Office (NAO) published a report entitled '*Setting the Records Straight*' [2] which noted numerous problems with the keeping of paper case-notes. Among the hospitals studied, 12 of the 16 kept multiple sets of case-notes for some patients, which could lead to confusion in administering care. Among 121 clinics, only two-thirds of case-notes were at hand for immediate use, and although most were located in adequate time, on some occasions (up to 3%) the search was fruitless and the patient was unable to receive their consultation. This has serious implications for the continuity of patient care, and may force a delay in surgical procedures or other interventions because patient history cannot be verified. It carries professional risks to the duty of care of the clinical team in not being able to make informed decisions. It also imposes an unnecessary financial burden due to wasted time for staff and patients. Missing case-notes can bias clinical audit, thus skewing the information used to monitor and advance clinical practice. For example, an audit of antenatal risk factors found that 6.4% of the case-notes were missing. Although

this sounds like a relatively small proportion, the suggestion was that this was non-random due to clinicians holding onto interesting cases for research or further discussion [3]. As well as entire case-notes going missing, individual test and procedure results, and sometimes episodes of care can be missing from the file. This again may delay timely care leading to poorer outcomes and subject the patient to duplicate risky invasive processes. It also wastes public money and staff time [2].

Since the publications of this NAO report two decades ago, there have been considerable advances in the use of electronic clinical systems in healthcare. Nevertheless, the UK is still a long way from having a comprehensive electronic patient record, let alone being able to use and share it effectively. Swansea University hosts the UK Multiple Sclerosis (MS) Register [4]. When the Register was being established in 2009, a survey of clinical recordkeeping methods in NHS Neurology clinics across the UK was carried out. Of the 47 respondent clinics (N = 83), 5 still used paper records only, 8 stated that they used a word processor package, and only 10 reported using an MS-specific clinical IT system [5]. Purposive action was needed in order to facilitate data collection for the MS Register, and an open-source clinical system was adapted and made available to participating sites. There does not seem to be any reason to assume that Neurology is vastly different to most other disciplines, and so the significance of this is that the pace of change towards electronic systems is slow, and that without the use such systems, the effective use of data is hampered. Although there are moves towards increasing the use of clinical systems, data sharing and research opportunities in the UK NHS [6,7], these remain largely aspirational for many care practitioners. The main focus for health practitioners is on delivering optimal patient care, and with the current high demands, staff are inevitably limited in the effort they can dedicate to other pursuits without strategic-level decisions to provide sufficient funding, training and time [8,9]. Until these issues can be addressed effectively, problems due to the non-use of case-note data will continue.

However, even when a clinical IT system is in place, there are issues that impact on data availability for use. The traditional position is of data in silos, such that primary care data are generally available only within the practice and not systematically shared with hospitals. Indeed, even within a given hospital, data are often still held on administrative or departmental systems that may or may not communicate with each other. A team of healthcare professionals may be involved in an episode of care, some of whom may enter data into the system, and some of whom may record data on paper to be transcribed later by an administrator. Although it may never be intended that every piece of information should reside in the electronic system, this does introduce the possibilities of error and non-entry of important data. It is also the case that when an electronic system is implemented, a judgement call has to be made on the bases of relevance and resources as to how much back data are entered into the system. Furthermore clinical systems may have usability deficiencies and data entry constraints that prove difficult to work with resulting in major problems such as were seen with the EPIC system at Cambridge University Hospitals NHS Foundation Trust (England) [10,11]. Thus there are issues of data quality and completeness within individual systems to contend with before we consider interoperability problems which can limit combining information from different systems. Without this, the data are still in silos, albeit now electronic ones. A case in point is that of a vulnerable little boy who died in 2011 following systematic abuse. There were multiple visits and reports to the GP practice, health visitor, community paediatrics and emergency departments. Each instance was isolated as the data on presentations elsewhere were not available. Because of this, instances were not seen in context and the problems were not identified in time to save the life of the child [12].

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