

This response was submitted to the consultation held by the Nuffield Council on Bioethics on 'The linking and use of biological and health data' between 17 October 2013 and 10 January 2014. The views expressed are solely those of the respondent(s) and not those of the Council.

Nuffield Council on Bioethics: The linkage and use of biological and health data

1. Do biomedical data have special significance?

The data is collected by medical professionals and imposing additional burdens to satisfy secondary uses of the data could negatively affect patient care.

Many dentist will record patient data in different ways even when using the same software without negatively affecting patient care. The requirement to record information in a more standardised manner may distraction from the primary need to provide the best quality of patient care.

2. What are the new privacy issues?

There is a real lack of understanding on the part of patients about how medical information is used in a clinical setting. Many patients fail to fully disclose their medical history, sometimes this due to the stigma associated with a particular condition but often it simply reflects a lack of appreciation of how a complete medical history is relevant. Similarly most patients are unaware that information can be passed to third parties and how it can be used to improve patient care.

At least 75 per cent of dental practices perform at least some private treatment. The requirement to collect both NHS and privately held patient data raises potential problems. Mechanisms that will permit and promote the release of patient data from private practice need to be established.

3. What is the impact of developments in data science and information technology?

There is the danger that big data will be used to replace existing mechanistic studies, whilst it will suggest new relationships and associations it cannot replace existing experimental approaches.

It will be difficult to predict or restrict the linkage to health data to other datasets. New and emerging uses of the data may present additional problems. The ability to replicate electronic medical records means the ability to restrict their dissemination over time will be difficult.

4. What are the opportunities for, and the impacts of, the use of linked biomedical data in research?

The immediate impact on patient care may be limited which may undermine public enthusiasm for the process of data collection.

The use of patient data for commercial purposes suggests that patients are being exploited for financial gain and should require additional specific explicit patient consent.

Databases must be free from commercial influence that might want to limit or bias the data available.

5. What are the opportunities for, and impacts of, data linking in medical practice?

The ability to evaluate the performance of interventions based on real-world data will allow a realistic assessment of the interventions available. The linkage of medical data will allow the

relationship of oral health to other systemic conditions like cardiovascular disease and diabetes to be assessed. This type of holistic view is only possible using linked healthcare records.

The ability to full assess risk factors for oral health including medications used to treat systemic conditions.

6. What are the opportunities for, and the impacts of, using biomedical data outside biomedical research and health care?

The ability to use records to identify the risk of future disease risk will become increasingly possible. The use of this relationship has the potential to define an uninsurable category of patient who will be excluded from mainstream private dental care.

7. What legal and governance mechanisms might support the ethical linking of biomedical data?

Patients need an effective method to be able to opt-out. The ability to replicate data means that specific mechanisms must be established to opt-out from all copies and forms of the linked dataset. True consent will require a method to inform patients each time their medical records are linked with new datasets. Consent to use linked medical records does not necessary provide agreement to link that data with other sets of social or economic data.