

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 linking and use of biological and health data

Comments from Christian Medical Fellowship

The Christian Medical Fellowship (CMF) has over 4,000 doctor members and around 1,000 medical student members and is the UK's largest faith-based group of health professionals. A registered charity, it is linked to about 70 similar national bodies in other countries throughout the world. Our doctrinal beliefs and ethical values are outlined on our website: <http://www.cmf.org.uk/>.

One of CMF's aims is 'to promote Christian values, especially in bioethics and healthcare, among doctors and medical students, in the church and in society'.

We submitted detailed responses to the Nuffield consultations on emerging technologies, donor conception and novel neurotechnologies, all available on our website: <http://www.cmf.org.uk/publicpolicy/submissions/>

CMF welcomes the opportunity to contribute to this public consultation. Our comments focus on one specific issue that has not been directly addressed by the consultation but which is of relevance to the inquiry.

The Nuffield consultation paper notes, as background to the consultation, that large-scale biomedical research resources (biobanks) collect data from many participants that combine the comprehensive description of observable characteristics of people, their [health records](#), analyses of their genomes and/or other large data sets.

The consultation also wishes to consider how data might be collected as part of a diagnostic or treatment procedure, principally on the ways in which these data may be linked and analysed together in order to generate insights that can be applied in the treatment of individuals and populations.

The paper notes that health-related data (eg., imaging data, laboratory test results and other quantitative data) from millions of individuals are a very valuable resource for medical research. The data collected when people are recruited to biobanks can be linked to pre-existing data, for example from [health records](#), administrative databases or disease registries

The concern we have, however, is that there is a source of important health record data that is not being routinely collected and therefore cannot be used in medical research nor in generating insights that can be applied to treatment of individuals.

Commissioned providers of termination of pregnancy (ToP) in England are not required to routinely record the patient's NHS number in patient records, thus subsequent female health events cannot easily be linked back to the said

operation, and longitudinal research is almost impossible. Nor do the standard abortion notification forms (HSA1 and HSA4) ask for this data.

This puts England behind the rest of Europe and the World regarding this evidence, including behind Scotlandⁱ and so epidemiologists are unable to calculate certain important female health risks for this English procedure.

In contrast, nearly all other procedures commissioned by the NHS requireⁱⁱ the NHS number to be used for private procedures.ⁱⁱⁱ

We therefore propose that routine record keeping of NHS numbers for each ToP should be put in place, as for any other female operation, in order to improve care, hold all providers accountable for the healthcare outcomes of their patients and to enable linkage of female patient events to any other hospital or NHS commissioned episode in their life. The number should be recorded on both healthcare records and statutory notification forms.

It would also facilitate invaluable English longitudinal studies of patient outcomes from termination of pregnancy, as has been carried out in Europe and Scotland.^{iv} This research is overdue.

While concerns may be expressed about confidentiality and privacy protection for women undergoing ToP, all good epidemiological longitudinal research is confidential, which would include research on the outcomes of ToP's linkage with the female health record. Indeed, Finland has had a computerised abortion registry since 1983 and Denmark since 1973 so a combined total of 70 years data entry with no breaches of confidentiality.

We would be grateful if you would consider this concern when reviewing the linking and use of public health data.

ⁱ Bhattacharya S, Lowit A, Bhattacharya S. et al- Reproductive outcomes following abortion: A national register-based cohort study in Scotland. *BMJ Open* August 2012,e000911--*Scottish paper published in Aug 2012*

ⁱⁱ <http://www.connectingforhealth.nhs.uk/systemsandservices/nhsnumber/staff/commissioning>

ⁱⁱⁱ <http://www.england.nhs.uk/wp-content/uploads/2012/12/sc-b-serv-conds.pdf>. See paragraphs 23.5 and 28.2.4

^{iv} Eg. Shah PS, Zao J. Induced termination of pregnancy and low birthweight and preterm birth: a systematic review and meta-analyses. *BJOG* . 2009 Oct;116(11):1425-42.
Swingle HM, Colaizy TT, Zimmerman MB, Morriss FH, Jr. Abortion and the risk of subsequent preterm birth: a systematic review with meta-analyses. *J Reprod Med*. 2009 Feb;54(2):95-108.
Bhattacharya S, Lowit A, Bhattacharya S. et al- Reproductive outcomes following abortion: A national register-based cohort study in Scotland. *BMJ Open* August 2012,e000911--*Scottish paper published in Aug 2012*