

## **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 to be linked backed 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 Scotland<sup>i</sup> 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 require<sup>ii</sup> the NHS number to be used for private procedures.<sup>iii</sup>

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.<sup>iv</sup> 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.**

## **Respondent's form**

Please complete and return with your response by **10 January 2014**. We will **not** publish your name without your express permission.

### **Your details:**

Name: Philippa Taylor\_\_\_\_\_

Organisation (if applicable): Christian Medical Fellowship\_\_\_\_\_

Email: philippa.taylor@cmf.org.uk\_\_\_\_\_

### **About your response:**

**Are you responding personally (on your own behalf) or on behalf of your organisation?**

Organisation

**May we include your name/your organisation's name in the list of respondents that will be published in the final report?**

Yes

**If you have answered 'yes', please give your name or your organisation's name as it should appear in print (this is the name that we will use in the list of respondents in the report):**

Christian Medical

Fellowship\_\_\_\_\_

**May we quote your response in the report and make it available on the Council's website when the report is published?**

Yes, attributed to my organisation

**\*If you select this option, please note that your response will be published in full (but excluding this form), and if you wish to be anonymous you should ensure that your name, and any other identifying information, does not appear in the main text of your response. The Nuffield Council on Bioethics cannot take responsibility for anonymising responses in which the individual or organisation is identifiable from the content of their response.** Obtaining consent to publish a response does not commit the Council to publishing it. We will also not publish any response where it appears to us that to do so might result in detriment to the Council's reputation or render it liable to legal proceedings.

**Why are you interested in this consultation? (Tick as many as apply)**

- Personal interest (please state):  
\_\_\_\_\_
- Professional interest – biomedical researcher
- Professional interest – Caldicott guardian
- Professional interest – clinician
- Professional interest – data owner
- Professional interest – data protection officer
- Professional interest – information technology professional
- Professional interest – knowledge and information management professional

Other professional interest (please state):

NGO

Government

Academic interest

Legal/regulatory interest

General interest

Other (please state):

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**Please let us know where you heard about the consultation:**

Received notification by email

Newspaper, radio or television

Nuffield Council on Bioethics website

Twitter

Facebook

Other website (please state):

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Other (please state):

**Using your information**

We ask for your email address in order that we can send you a link to the report when it is published and notify you about activities related to this project. (Please note that we do not make your email address available to anyone else, and we do not include it with the list of respondents in the report.)

**May we keep your email address for these purposes?**

Yes

**Would you like to receive our regular newsletter by email which provides you with information about all of the Council's activities?**

Yes

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<sup>i</sup> 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*

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

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

<sup>iv</sup> 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.

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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*