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6th May 2024

**Subject: Sending British citizens' genetic and patient data to hostile states**

Dear Rory, colleagues, and successors,

Late last year you invited medConfidential to examine your processes and then withdrew your cooperation. We continued with your public materials and published as we said we would.<sup>1</sup> On the basis of your previous invitation, we now add questions on whether biobank continues to send British citizens' genetic and (NHS) patient data to China or other "hostile states".

You should already be aware of the recent HM Government briefing to UK Universities about hostile states targeting UK research.<sup>2</sup> The biobank website suggests at least 7 of the last 20 projects that biobank has approved (or at least, as publicly described as approved) were at Chinese institutions.<sup>3</sup>

We understand there was no meaningful change in biobank processes after the 2022 article about biobank access in China, and similarly there was no meaningful change following our 2023 questions which included concerns about biobank making data available to a US shell company run by Russian nationals. In the latter case, we understand biobank's private dismissal was "more is more"; presumably including "more" revenue to biobank in return for "more" data to hostile states, reflecting the substance of HMG's concern.

No one should be satisfied that there is still no clarity on exactly what patient data Biobank has disseminated to what researchers where, despite this being a constant question for multiple years. This is an answerable question to which there should be no space for concern.

With biobank's lack of transparency, and with biobank continuing to sending British citizens genetic and patient data to China, and the recent HMG briefing, we have some questions:

**...on Data**

1. What data fields (from which suppliers) has biobank received payment for and consequently sent to *China* in the period of concern to HMG<sup>4</sup>?
2. What data fields (from which suppliers) has biobank received payment for and consequently sent to *Russia* since March 2022?

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<sup>1</sup> <https://medconfidential.org/wp-content/uploads/2023/10/biobank.pdf> and <https://medconfidential.org/wp-content/uploads/2023/11/biobank-again.pdf>

<sup>2</sup> <https://www.theguardian.com/technology/2024/apr/26/foreign-states-targeting-sensitive-research-at-uk-universities-mi5-warns>

<sup>3</sup> <https://www.ukbiobank.ac.uk/enable-your-research/approved-research>

<sup>4</sup> Since that period is not public, perhaps since the 2022 China article?

3. We have previously asked whether biobank satisfies obligations to NHS data providers in an application form which does not ask the questions necessary to satisfy those obligations. Is Biobank satisfied that it will pass an NHS England audit?
4. Given HMG concerns about “commercial” priorities of states to which you have granted access, does biobank satisfy all obligations to the NHS and HMG about public benefit beyond new treatments being developed that the NHS and the UK public purse must pay high prices for (as with [Kaftrio](#))?

### **...on Transparency**

As biobank only makes available the bare minimum of information on projects – title, date, institution, lead investigator, and a description<sup>5</sup> – there is no information in the public domain whether data was disseminated beyond biobank’s control to the recipients publicly listed.

5. Which projects are restricted to what biobank terms a “trustworthy research environment”, and how does biobank ensure that individuals who *use* the environment are only those whom biobank has approved?
  - a. Who decided that the biobank environment is trustworthy?
  - b. Does the current opacity have the confidence of biobank cohort representatives?<sup>6</sup>

### **... on GP Data**

6. Has biobank disseminated to China any of the English GP patient records it “acquired” with an “unclear” legal basis from TPP either a) before or b) after the BMA asked biobank to regularise the legal basis? (we note biobank continues to refuse to regularise that basis)
7. Do current biobank practices around risk satisfy all promises to the biobank cohort and other institutional data providers?

We understand biobank argues that it makes data available as that is what the biobank cohort signed up for, “more is more”, but we also note biobank have been unwilling to publicly substantiate that case for the data biobank says it provided to an organisation which claims to have customers in the insurance industry.

medConfidential continues to believe that data can be used for public good when it is consensual, safe, and transparent. We hope to hear from you that UK Biobank’s ongoing practice of sending British citizens’ genetic and (NHS) patient data to China and other hostile states does not diverge from the expectations of relevant authorities and stakeholders.

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<sup>5</sup> <https://www.ukbiobank.ac.uk/enable-your-research/approved-research>

<sup>6</sup> For the avoidance of doubt, the opacity does not have the confidence of medConfidential, but it is easy for you to rectify this.

Yours sincerely,



Phil Booth, medConfidential



Sam Smith, medConfidential

Cc University of Oxford, DHSC, NHS England, NDG, MRC, biobank board<sup>7</sup>

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<sup>7</sup> Those on the board for whom we have easy contact details for. We presume board members receiving it will act responsibly to share it with others.