

Coercive collection of DNA is unethical and damaging to the future of medical research

The compulsory collection of DNA being undertaken in some parts of the world is not just unethical, but risks affecting people's willingness to donate biological samples and thus contribute to the advancement of medical knowledge and the development of new treatments, says a paper in the *European Journal of Human Genetics*, published online* today [18 January 2021].

Citing abuses being carried out in China, Thailand, and on the US/Mexico border, the authors¹ call on scientific journals to reexamine all published papers based on databases that do not meet accepted standards of ethical approval, and demand an end to collaborations between academic institutions worldwide and those in countries carrying out unethical DNA collections. They also advocate that companies making equipment used in DNA analysis should stop sales to the institutions involved in ethically tainted genetic research.

While journals ask that studies submitted to them should have ethical approval, they may fail to recognise that some ethics committees do not abide by expected ethical standards. Citing the compulsory collection of DNA samples from ordinary people being carried out by the Chinese authorities in Xinjiang province as part of a programme of surveillance and control, the authors say: «It appears that almost half of over a thousand articles describing forensic genetics studies in Chinese populations have at least one co-author from the Chinese police, judiciary, or related institutions. It is impossible to carry out forensic population genetics research in China independently from the Chinese authorities. All this literature is thus potentially ethically tainted.»

The paper calls on publishers to conduct a mass reassessment of the literature and to require further information on consent and ethical approvals, in addition to considering whether the studies fulfill the basic ethical requirements for non-maleficence, beneficence, justice, and veracity. «Such an assessment would be important if, in the future, any doubt arises about the data and the uses to which they may be put.»

Companies should reconsider their position too, says the paper. Thermo Fisher Scientific has decided to stop sales of equipment to Xinjiang police forces, but such action by one company alone is insufficient to tackle the problem. «The only effective way would seem to be to stop sales to police and judiciary forces across China of products used in the identification of humans by means of molecular genetics. Other Western suppliers, such as Promega and QIAGEN, should follow suit.»

The example of Kuwait is encouraging, say the authors. In 2015, the Kuwaiti government became the first in the world to introduce a law requiring the compulsory collection of DNA samples from all citizens, residents, and visitors to the country. Such a measure was introduced purportedly to discourage terrorism, but many suspected that it could lead to genetic discrimination against some vulnerable minorities. The following year, after an international campaign against the measure, the law was dropped.

«While China, the USA, and Thailand are very different countries from Kuwait, both in their size and their leadership, the Kuwaiti example gives us reason to hope that international pressure may have an effect. We are concerned that the growing public awareness of abusive DNA collections will have a detrimental effect on the image of genetics in the wider world,» say the authors.

«In this time of COVID-19, Chinese science is increasingly under scrutiny from all quarters. The country's reaction to the pandemic has been widely praised. It is surely not in their interest to damage their standing in the scientific world by continuing with what are clearly unethical and discriminatory practices,» they conclude.

*<https://www.nature.com/articles/s41431-020-00786-6>

¹Dr Francesca Forzano, Prof Maurizio Genuardi, Prof Yves Moreau, writing on behalf of the European Society of Human Genetics