

**Impact case study (REF3b)**

<p><b>Institution:</b> Queen Mary University of London (QMUL)</p>
<p><b>Unit of Assessment:</b> C17 (Geography, Environmental Studies and Archaeology)</p>
<p><b>Title of case study:</b> Regulating the forensic use of bioinformation</p>
<p><b>1. Summary of the impact</b></p> <p>Bronwyn Parry’s research into the ethical, legal and social implications of the storage and use of biological materials has had a direct impact on the UK government’s storage and use of DNA material for forensic investigation. Parry’s published research on the political-economic and cultural geographies of bioinformation led to her invitation in 2007 to become a member of the Nuffield Council on Bioethics. The Council’s subsequent report on <i>The Forensic Uses of Bioinformation</i> (2007), on which Parry was a lead author, directly influenced the EU Court of Human Rights’ (2008) <i>S and Marper</i> judgement and the subsequent UK Crime and Security Act 2010 which significantly restricted the use by the police of the UK National DNA Database in criminal investigations.</p>
<p><b>2. Underpinning research</b></p> <p>Parry, working in the School of Geography at Queen Mary University of London from 2004 to 2012, has conducted a series of research projects on the ethical, legal and social implications of the storage and use of biological materials and proxies, including plant and animal specimens, human tissue samples and DNA sequences. This work has examined both commercial processes and government-led bio-surveillance initiatives. Her monograph <i>Trading the Genome: Investigating the Commodification of Bio-Information</i> (Columbia University Press, 2004) examined the commercial use of biological materials collected from plants, animals, fungi and other organisms in the US pharmaceutical industry. It argued that the biotechnologies through which these collected organic materials were transformed (such as MRI scans or DNA sequences) have similar effects as other informational technologies (such as digital MP3 files for music) in that they enable biological materials to be stripped down and rendered into new forms, including those which are purely informational (such as sequenced DNA coded onto databases). This has, in turn, allowed them to be circulated within a global bioinformational economy with new effects, and raising new questions, about the ownership, regulation and use of these biological resources.</p> <p>Subsequent published work (Gere and Parry 2006; Parry 2005, 2008a) has used this theoretical framework to direct attention to the bioethical and cultural implications of the storage and use of human tissue as ‘bio-information’ in biomedical research. Parry’s research has examined human tissue collections, including those of whole organs such as brains stored in brain banks, and issues of public concern such as the Alder Hey and Bristol scandals over the retention of children’s body parts for medical research. In this work she has investigated the implications of human tissue collections ‘being progressively commuted into a series of new biotechnological artifacts: cryogenically stored tissue samples, cell lines, isolated sequences of DNA, scans, digital images and technoscientific “tools” such as genetic test kits’ (Parry and Gere 2006 p.139). She has also demonstrated that regulatory dilemmas over how these biotechnological artifacts can be dealt with arise because of their simultaneously corporeal and informational nature. In relation to DNA sequences in particular she argued that they are ‘an informational resource of stunning richness and intricacy’, concluding that: ‘In relation to DNA archives we have a resource that seems to be both physically and informationally infinite, replicable any number of times without being used up, but also replete with potential for different kinds of analysis.’ As a result, these archives demonstrate an ‘almost inexhaustible capacity to lend themselves to unanticipated uses and manipulations’ (Gere and Parry, 2006 p. 52-3). It was as a consequence of this work that Parry was invited to become a member of the Nuffield Council on Bioethics in 2007.</p> <p>This research has examined both the implications of the ‘information-rich’ nature of these biological resources and their human particularities: their associated sensitivity as ‘personalised data’; the implications for individuals’ autonomy and privacy of retaining these samples or data; the questions</p>

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of intimacy and distance these resources raise (Parry, 2008b); and the associated need for robust regulation, ethical monitoring and oversight to prevent inappropriate or unauthorised use. Parry's work has, therefore, involved careful interpretation of these forms of regulation. Her examination of 'the multiply constituted and complex range of transactions that attend the contemporary circulation of human body parts and tissues' includes several dimensions (Parry, 2008 p. 1134). 1. Analysis of regulatory mechanisms that operate through varied forms of commodification; 2. Understanding the cultural and ethical implications of ways of extracting, sharing or giving these biological resources – and the compensations that are received for them – that go far beyond a conventional dichotomy between 'the gift' and 'the market' (including a Wellcome Trust funded book and exhibition *Mind Over Matter* (2011) designed to provoke debate about brain donation); and 3. Regulatory mechanisms implicated in regimes of state biosurveillance (for a later statement see Parry, 2012). It is this latter strand that has had direct impact via legislation on UK public policy relating to the storage and use of DNA materials by the police.

### 3. References to the research

- Gere, C.M. and Parry, B.C. (2006) "The flesh made word: banking the body in the age of information". *BioSocieties*, 1:1 pp. 83-98.
- Parry, B.C. (2004) *Trading the Genome: Investigating the commodification of bio-information* (Columbia University Press, New York)
- Parry, B.C. (2005) "The new Human Tissue Bill: Categorization and definitional issues and their implications" *Genomics, Society and Policy*, 1:1 pp.74-85.
- Parry, B.C. (2008a) "Entangled exchange: Reconceptualising the characterisation and practice of bodily commodification" *Geoforum*, 39:3 pp.1133-44.
- Parry, B.C. (2008b) "Inventing Iris: negotiating the unexpected spatialities of intimacy," *History of the Human Sciences*, 21:4 pp. 34-48
- Parry, B.C. (2012) 'Domesticating bio-surveillance: "containment" and the politics of bioinformation,' *Health and Place*, 18:4 pp. 718-25
- Parry, B.C. and Gere, C. M. (2006) "Contested Bodies: Property Models and the Commodification of Human Biological Artefacts" *Science as Culture* 15:2 pp.139-58
- Quality: All journal articles are in international peer-reviewed publications.

#### Supporting Award

**Grant:** People Award and Extension Award

**Title:** Mind Over Matter. **Funder:** The Wellcome Trust. **Dates:** 2008-2011. **Amount:** £ 60,000

[www.mindovermatterproject.co.uk/about.html](http://www.mindovermatterproject.co.uk/about.html)

### 4. Details of the impact

Parry was appointed as a lead author for the Nuffield Council on Bioethics' report on *The Forensic Uses of Bioinformation: Ethical Issues* (published September 2007). The report was prompted by concern over the progressive enlargement of the UK's National DNA Database (UKNDNAD) and the perceived lack of adequate regulation and ethical oversight of its operation which had extended from domestic policing operations to counter-terrorism initiatives. The Council's published terms of reference state that it produces its reports with 'a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body.' Parry's work was central to the production of the report. She co-authored several sections, including taking primary responsibility for the sections in the first and second chapters that specifically relate to the nature of bioinformation. Here she furthered the thesis developed in her research that DNA must be understood as both a corporeal and an informational resource. This contention was key to a series of recommendations that followed in the Report regarding the policy and protocols that should attend the use of both the biological samples of DNA drawn from offenders and the DNA profile/digitally rendered sequence later derived from them. The two resources should, Parry argued, be subject to different regimes of regulation as the biological samples, which have historically been retained for long periods of time, remain sources of highly personalised medical and/or genealogical information, access to which should be strictly delimited.

This particular argument was taken up as a central tenet of the Report (see Executive Summary paragraphs 9 and 10). In addition to this Parry co-authored what proved to be the most sensitive and politically charged section of the Report, chapter six, which discussed the most contentious uses of the samples and profiles accumulated on the UKNDNAD. These include research dedicated to familial searching (identifying offenders through their relatives), ethnic inferencing and potential behavioural genetic research designed to establish a pre-conceived 'genetic predisposition to crime' amongst racial groups currently over-represented on the Database.

The report has had significant impacts on UK public policy:

**i. Dissemination and discussion of the Report's recommendations**

*The Forensic Uses of Bioinformation* report was very widely disseminated and discussed in the public domain and with relevant government agencies. This includes: An event at the Labour Party Conference, Bournemouth (25/9/07); Capita National Forensics Conference, London (31/3/08); Public discussion events at Manchester Science Museum ("Towards a Universal DNA Database", 8/4/08), Lewisham Community Police Group (13/5/08) and the Dana Centre, London ('Crime Scene Crackdown', 26/6/08). Parry has also given workshops on the limits to the use of DNA in court to the following agencies: The Bar Council, Bar Standards Board, Criminal Bar Association, Law Society, Solicitors Regulation Authority, Criminal Law Solicitors Association, Judicial Studies Board, Forensic Science Society and the British Academy of Forensic Sciences. In addition, the Report was downloaded from the Nuffield Council's website more than 40,000 times from September 2007 to the end of 2008.

**ii. Case of S and Marper v UK**

In December 2008, the European Court of Human Rights ruled on the case of two applicants Mr. S. (who requested that his name not be disclosed) and Mr. Marper who complained under the Convention for the Protection of Human Rights that the authorities had continued to retain their fingerprints and cellular samples and DNA profiles after the criminal proceedings against them had ended in an acquittal or had been discontinued. In finding for the applicants that the blanket policy in the UK of indefinitely retaining DNA profiles/samples and fingerprints, regardless of the outcome of arrest, was disproportionate the Court cited the Nuffield Council's Report. In doing so, the Court explicitly referred to Parry's argument that 'the retention of fingerprints, DNA profiles and biological samples is generally more controversial than the taking of such bioinformation, and the retention of biological samples raises greater ethical concerns than digitised DNA profiles and fingerprints, given the differences in the level of information that could be revealed' (Case of S and Marper v. UK para 38) and noted the Report's 'concerns at the increasing use of the DNA data for familial searching, inferring ethnicity and non-operational research' which had been co-authored by Parry.

**iii. Crime and Security Act 2010**

This European Court of Human Rights judgement has resulted in a significant revision of the way the UK government constructs, maintains and employs the UKNDNAD, resulting in a total reformation of the UK's relevant legislation and policy. The recommendations of the Report were employed by the Director of Forensic Services for the Metropolitan Police and the Home Office in the drafting of the *Crime and Security Bill* (2009). The Report was also referred to on several occasions in debates and reports relating to the Bill: Paul Holmes MP, National DNA Database Westminster Hall debate, 9/12/09 ([www.theyworkforyou.com/whall/?gid=2009-12-09a.117.1](http://www.theyworkforyou.com/whall/?gid=2009-12-09a.117.1)) ; Andrew Dismore MP, House of Commons Crime & Security Bill Report Stage, 8/3/10 ([www.publications.parliament.uk/pa/cm200910/cmhansrd/cm100308/debtext/100308-0009.htm](http://www.publications.parliament.uk/pa/cm200910/cmhansrd/cm100308/debtext/100308-0009.htm)); Parliament's Joint Committee on Human Rights Report on Scrutiny of the Crime & Security Bill, 8/3/10 ([www.publications.parliament.uk/pa/jt200910/jtselect/jtrights/67/67.pdf](http://www.publications.parliament.uk/pa/jt200910/jtselect/jtrights/67/67.pdf)); and The Commons Home Affairs Committee report on the National DNA Database, 8/3/10 (<http://www.parliament.uk/business/committees/committees-archive/home-affairs-committee/10308/>) which included evidence submitted by the Council.

The passage of the Crime and Security Act (April 2010) amended the operation of the UKNDNAD in significant ways which responded to the differences between corporeal and informational biotechnologies as identified by Parry. Thus, DNA profiles of non-convicted individuals were to be

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kept for a maximum of 6 years (3 years for under 18s); all biological samples were to be destroyed; and DNA profiles of volunteers and children under 10 were no longer to be held on the database.

**iv. Protection of Freedoms Act (2012)**

More recently, the Coalition Government announced that it intended to “adopt the protections of the Scottish model for the DNA database” in its Protections of Freedom Act (2012) which became law in May 2012. The law changed to reflect many recommendations of the Nuffield Council’s report, in particular: all biological samples to be destroyed within six months; those convicted of an offence – indefinite retention; those arrested / charged but not convicted of minor offences – no retention; those arrested / charged but not convicted of serious offences – three year retention; and separate provision for minors.

The significance and scope of this impact relates directly to all those whose DNA samples are, or would have been, held on the DNA database and, more broadly, all UK citizens whose relationships to authority are increasingly defined through regimes for the storage and use of bioinformation.

**5. Sources to corroborate the impact**

- i. Nuffield Council on Bioethics (2007) *The Forensic Uses of Bioinformation: Ethical Issues*. [www.nuffieldbioethics.org/sites/default/files/The%20forensic%20use%20of%20bioinformation%20-%20ethical%20issues.pdf](http://www.nuffieldbioethics.org/sites/default/files/The%20forensic%20use%20of%20bioinformation%20-%20ethical%20issues.pdf)
- ii. Case of S and Marper vs the United Kingdom, European Court of Human Rights (2008) [www.bailii.org/eu/cases/ECHR/2008/1581.html](http://www.bailii.org/eu/cases/ECHR/2008/1581.html);
- iii. For media coverage up to 8<sup>th</sup> May 2009 [www.nuffieldbioethics.org/bioinformation/bioinformation-media-coverage](http://www.nuffieldbioethics.org/bioinformation/bioinformation-media-coverage)
- iv. For update on the Law [www.nuffieldbioethics.org/bioinformation/bioinformation-what-bioinformation](http://www.nuffieldbioethics.org/bioinformation/bioinformation-what-bioinformation)
- v. Protection of Freedoms Act 2012 [www.gov.uk/government/publications/protection-of-freedoms-act-2012-dna-and-fingerprint-provisions/protection-of-freedoms-act-2012-how-dna-and-fingerprint-evidence-is-protected-in-law](http://www.gov.uk/government/publications/protection-of-freedoms-act-2012-dna-and-fingerprint-provisions/protection-of-freedoms-act-2012-how-dna-and-fingerprint-evidence-is-protected-in-law)

*Individuals to corroborate the impact:*

- i. Director, Nuffield Council on Bioethics (impacts i – iv).
- ii. Project manager for the Nuffield Council on Bioethics report *The Forensic Uses of Bioinformation: Ethical Issues* (2007) (impacts i – iv).