

# International standards for DNA databases?

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**[www.dnapolicyinitiative.org](http://www.dnapolicyinitiative.org)**

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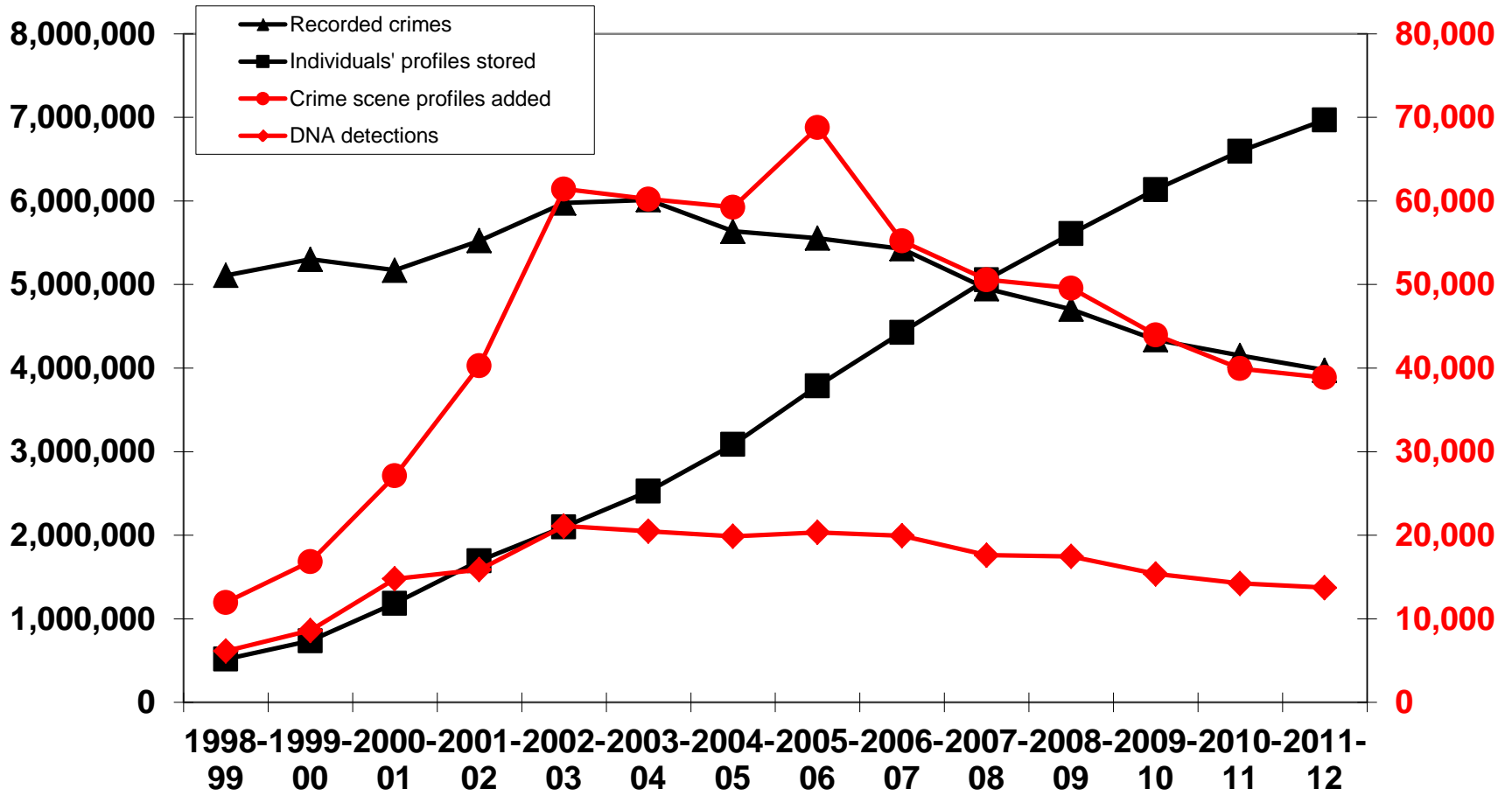
# The UK National DNA Database

- New Labour government made 2 changes to law: retention of DNA profiles of innocent people (2001); collection of DNA on arrest (rather than charge) (2003) for all recordable offences
- Led to growing public controversy
- European Court of Human Rights ruled in breach of right to privacy (Marper case 2008)
- Protection of Freedoms Act 2012: 1.7m DNA profiles removed, 7.75m samples destroyed

# People's concerns included

- the personal nature of their DNA;
- being treated like a criminal (unfairness);
- the growth of a 'Big Brother' state and potential misuse of data by government (tracking individuals or groups of people or their families);
- potential loss of data or misuse of data (including by corrupt police officers, commercial providers or infiltrators);
- the implications of having a 'criminal' record for the rest of their life (including implications for employment, visas or treatment by the police);
- the possibility of being falsely accused.

# DNA detections are driven by the number of crime scene profiles loaded per year



Sources: UK DNA database annual reports and Home Office crime data

# Removal of 1.7m profiles did not reduce the role of the NDNAD in solving crimes

- NDNAD Annual Report 2015/16: 13,375 detections (0.37% of recorded crimes – more or less constant since 2002/03)
- 2014/15 match rate (crime scene to subject) 63.2% (increased year-on-year)
- Number of crimes detected is driven largely by the number of crime scene DNA profiles loaded
- USA: 1,000 offender profiles uploaded, 8 investigations aided: 1,000 crime scene profiles uploaded, 407 investigations aided (Urban Institute, 2013)

# Lessons learned

- DNA databases raise concerns about **biosurveillance** (tracking of citizens and their families) and **discrimination** based on genetics or other data (especially police records of arrest, and data on ethnicity).
- DNA evidence is not foolproof.
- Storing innocent people's DNA does not help to solve more crimes.
- **Safeguards and scrutiny** are essential to prevent abuses and miscarriages of justice.
- Importance of maintaining trust

# The DNA Policy Initiative

[www.dnapolicyinitiative.org](http://www.dnapolicyinitiative.org)

- Aims: (i) to secure human rights safeguards for DNA databases globally; (ii) to engage civil society in debate
- What is best practice? E.g.
- When should DNA be collected?
- Whose DNA should be stored?
- How should access and uses be restricted?
- What safeguards are needed to prevent miscarriages of justice?
- When should cross-border sharing be allowed?



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## Overview

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India does not have a national DNA database. However, according to Interpol's 2008 survey it has used HID (Human Identification) software of a national design for the operation of regional (State) databases.

In 2007 a bill known as the Draft DNA Profiling Bill was piloted by the Centre for DNA Fingerprinting and Diagnostics, an autonomous organization funded by the Department of Biotechnology, Ministry of Science and Technology, Government of India. The Bill is being developed further by an expert committee before being considered by parliament. The DNA Profiling Bill looks to legalize the collection and analysis of DNA samples for forensic purposes and the creation of a national database. See below for further details.

## Resources

[\[edit\]](#)

### External links

- [CIS: A Public Meeting on DNA Profiling Bill in Delhi \(29th September 2012\)](#)
- [GeneWatch UK: INDIA DNA BILL: Collection of DNA \(12th September 2012\)](#)
- [GeneWatch UK: INDIA DNA BILL: Retention of DNA \(12th September 2012\)](#)
- [GeneWatch UK: INDIA DNA BILL: Uses of DNA \(12th September 2012\)](#)
- [GeneWatch UK: INDIA DNA BILL: Solving crimes \(12th September 2012\)](#)
- [Overview and Concerns Regarding the Indian Draft DNA Profiling Act \(6th September 2012\)](#)
- [Draft Human DNA Profiling Bill 2012 \(February 2012\)](#)
- [Centre for Internet and Society: An Overview of DNA Labs in India](#)
- [Centre for Internet and Society: The DNA Profiling Bill 2007 and Privacy \(25th April 2011\)](#)

### Press articles

- [First Post: Arushi trial: A double murder of forensic and investigation \(26th November 2013\)](#)



# Most countries now aim to remove innocent people's DNA records

- New EU Data Protection Directive
- All Council of Europe members are affected by the Council of Europe judgement e.g. Russia
- Portugal, Uzbekistan have backtracked from plans to store whole population's DNA
- Oklahoma rejected a law that lacked automatic expungement for innocent people
- Laws in Korea, South Africa, Brazil, Malaysia, Ireland..and a draft Bill in India include expungement
- ...but it is not always clear how this will work in practice

# Many policy areas remain contentious

- Collection of DNA is arbitrary in some counties but tightly controlled in others
- Requirements to destroy samples are in most new legislation, but not universal
- Data protection and privacy laws exist in some countries but not others
- Independent oversight may or may not exist
- Safeguards may differ for different agencies or categories of persons (e.g. use for national security, inclusion of missing persons, regional v national laws)
- Societal background influences public trust (e.g. history of dictatorship or apartheid, consequences of revealing non-paternity, attitudes to ethnic minorities)

# Scientific and technical standards vary

- Laboratory quality assurance (QA) may be lacking
- Police may be untrained in crime scene examination
- There can be a high risk of contamination
- Large populations require more discriminatory profile systems (more locii)
- Legal systems may deal poorly with DNA evidence: supporting evidence may not be required
- Legislation is not always implemented
- UK Forensic Regulator set up to deal with many of these issues
- Laboratory (but not crime scene) QA compulsory in USA and EU

# An important exception

- In 2015, Kuwait adopted a law to put its entire population and all visitors on a DNA database
- This law has been widely criticised, inside and outside the country
- There is particular concern about identification of family relationships e.g. non-paternity
- The law includes imprisonment of a year and a fine of up to 10,000KD (£23,500) for refusal to provide a sample
- The law also requires collection of DNA at borders without probable cause and with indefinite retention
- The regulations required to implement the law have not yet been issued
- Practicalities and costs are not yet resolved

# Towards best practice

- A growing global consensus on the need to destroy biological samples and remove innocent people's DNA profiles from DNA databases
- Increasing attention paid to technical and scientific standards: but many serious gaps in implementation
- Highly variable safeguards for DNA collection from suspects; restrictions on access, uses and data sharing across borders; and data protection/privacy standards
- Brazil law (2012) is 1 page, Ireland law (2014) is 233 pages
- More societal engagement and debate about safeguards is needed

# UN Special Rapporteur on Privacy

- *“...there is an ongoing need for greater public and policy debate as DNA databases expand around the world. The SRP intends to continue to engage with projects which aim to set international human rights standards for DNA databases, by establishing best practice and involving experts, policy makers and members of the public in open debate. It is expected that this engagement would contribute to best practice guidelines developed with civil society input, for feedback and discussion.” 8<sup>th</sup> March 2016*

# New technologies: an industry view:

Tim Schellberg, Gordon Thomas Honeywell,  
World Forensic Festival, Seoul, 2014

- *“...In the pursuit of justice, proposals will be inevitable to expand the databases to many more STR’s, full panels of Y STR’s, and SNPs...*
- *...The next ten years will also see a rise in the use of DNA database in civilian uses, such as for ID cards, and immigration. For example, within the next few years, we will likely see the first country move forward with a citizen-wide DNA database...*
- *...In the coming decades, personalized medicine will cause most of us to voluntarily submit our full human genomes to the health care industry. In exchange, we will hope to receive the best health care results possible. Consequently, public acceptance of genetic testing and big health care data will likely skyrocket.*
- *What will this all mean to the public policy debate related to criminal DNA databases? It will likely mean we will see a larger criminal DNA databases and aggressive applications to solve and prevent crime. ...”*

# New technologies: reality?

- Many countries' laws explicitly restrict stored data to non-coding DNA e.g. Ireland, Russia, Brazil, Argentina, Belgium, Germany, Portugal, Korea, South Africa.
- Some exceptions e.g. India draft law, Kuwait: in both countries proposals are contentious (India revised).
- EU's Prüm Decisions specify non-coding DNA
- In the USA: *"The term "DNA analysis" means analysis of the deoxyribonucleic acid (DNA) identification information in a bodily sample"*.
- Big issues with practicalities and costs e.g. South Africa has not yet begun to implement its 2013 DNA law, Brazil has collected only a few hundred DNA profiles since its 2012 law; US states are grappling with backlogs and controversies over untested rape kits.
- Plans to build DNA databases in some countries e.g, Pakistan, Libya, Syria are unlikely to progress



# Likely future developments?

- Potential for use of Rapid DNA testing e.g. at borders
- Also more (targeted) collection and retention of DNA from terrorist suspects (growth of counter-terrorism databases)
- Rapid expansion of DNA databases in a few countries (France?)
- More STRs required for larger databases and cross-border sharing (US, EU and potential new databases e.g. India)
- China plans a Y-STR database (Ge et al. Croat Med J. 2014;55:163-6 ): may have progressed at a local level
- Elsewhere, Y-STRs and mtDNA more likely to be used mostly in specific cases, and SNPs for identification in mass disasters (analysing degraded fragments)

# “Personalised Medicine”: reality?

- Mainly relevant to people with genetic disorders or cancer
- Idea of “genetic susceptibility” to most common diseases is largely discredited (some exceptions): although there is still a research role to identify disease mechanisms
- In the USA, the FDA is now regulating gene tests and there is new draft EU legislation (the IVD Regulation): this will limit the tests placed on the market
- “Care.data” and other medical record sharing schemes stalled or abandoned: issues with privacy/consent and costs
- Genome sequencing and medical interpretation will remain very expensive, and (mostly) pointless
- However, law enforcement has sought access to 23andMe and Ancestry.com data in several cases (23andMe says it had denied 4 requests affecting 5 users by Oct 2015: <http://fusion.net/story/218726/23andme-transparency-report/> )

# Likely future developments?

- Police/security service access to medical/research biobanks is likely in specific cases
- More ambitious plans (whole genomes from whole populations) less likely to be realised: if so, they will be led by research/health uses
- “Dual use” databases (medical and forensic) will be contentious and may struggle to comply with human rights and data protection law (especially in the EU)
- International standards required to maintain trust...

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- Email: [helen.wallace@genewatch.org](mailto:helen.wallace@genewatch.org)
- See also: Egyptian Journal of Forensic Sciences  
Volume 4, Issue 3, September 2014, Pages 57–63