

Solving Crimes While Protecting Genetic Privacy
Informed Consent

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Informed Consent

- Permission granted
- Benefits and risks
- “Full” knowledge of “possible” consequences
- Complete disclosure to make decision knowledgeably and with autonomy

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Privacy Concerns
Forensic Science, Criminal Investigation and
Judicial Proceedings Context



- Disclosure of personal information
- Access to DNA
- Coercion
- Vulnerable people and populations
- Inherent biases
- One person’s good intentions can be another’s intrusion
- Distrust
- ...



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Informed Consent

- Respect, Beneficence, Justice
- Information, Comprehension, Voluntary Participation
- Do no harm, treat fairly and equally, autonomy, no coercion













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Informed Consent

- Motivated to revisit due to advances in genomic capabilities
- Risk/Benefits






- Are past practices concomitant with capabilities and risks?
- Are they commensurate with today's expectations?

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Informed Consent Forensic Situations


- Research
- Reference samples from family members in missing persons or unidentified human remains cases
- Targeted analysis of an individual(s) during forensic genetic genealogy (FGG) cases to reduce an investigative burden
- Donors who provide their samples for validation studies (to include population studies and entry into databases that would be applied to forensic statistical calculations) to support implementation of procedures and operations of the forensic laboratory
- Family members that may contribute samples or obtain genetic information from a molecular autopsy
 - Balance between confidentiality and do no harm



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Informed Consent
Forensic Situations


- Samples obtained from other sources
 - Blood cards, medical samples, legally obtained samples
- Third party usage
- Populating databases
 - e.g., YHRD, EMPOP
 - Searching other government database (e.g., missing persons identification)
- “Contamination Control” databases
- ...



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Informed Consent Process

- Purpose for collection of samples
- Process to analyze the samples (to include type of data)
- Benefits (to donor, target, family, community, etc. as applicable)
- Risks (to donor, target, family, community, etc. as applicable)
- Access to data/reports by the donor
- Sample disposition
- Removal of data process (i.e., expungement)
- Process to ask questions/assessment of comprehension
- Follow up processes
- Voluntary, signed, and dated consent




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Genetic Markers/ Computational Power

- Autosomal STRs
- Y chromosome STRs
- X chromosome STRs
- Mitochondrial DNA
- SNPs (particularly large panels)

- Online data analyses



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General Privacy Concepts For Best Practices


Concept	Description
Fit-for-purpose	Describe legitimate purposes and gather informed consent for collecting genomic and other personal data
Data minimization	Collect only data necessary for the specified purpose
Storage	Retain personal data and samples only as long as necessary for the specified purpose
Transparency	Describe lawful and/or ethical basis for processing personal or genomic data in a fair, clear and understandable manner
Confidentiality	Provide privacy and security of personal data and samples
Accuracy	Ensure that personal data collected are correct, exact, up to date

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Risk Assessment

1. The risk and under what circumstances the risk may occur
2. The consequences should the risk occur
3. The likelihood of the consequences to occur
4. Processes or mechanisms are in place or need to be put in place to control or minimize the risk

- Part of a good quality assurance program to address root cause analysis, corrective action and preventive action
- Consider a probability/consequence matrix method to assess the overall severity of the contributing factors to each potential risk



<http://www.iso9001.com/confidence-and-risk-management-for-risk-assessment>

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General Security Measures to Mitigate Risk

Measure	Description or risk	Mitigation examples
Administrative controls	Data breach	Overall Information security program including training Policies and procedures to prevent, detect, contain and correct data violations Business/operation or data continuity plans and incident response plans
	Accountability	Designated database steward or risk officer Periodic external privacy impact studies
	Unauthorized access	Internal and external authorization processes Defined data retention policies for all files and stages of workflow Response plan for risk assessed or unperceived issues
Physical controls	Data access and availability	Designed database and storage mechanisms to limit proliferation of raw or processed data Inventory and logs on all systems that access and share data System, data and user level controls for system monitoring, encryption, tokenization, etc.
Technical controls	Unauthorized access	Authorization and authentication mechanisms such as multifactor sign in Registration of users System access logs Security of data when transmitted and during storage User initiated data deletion

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Informed Consent

- Benefits
- Risks
- Vulnerable
- Population, community, individual, situational, transient
- Informed
- Putting yourself in the subject’s position
- Proportionality

Forensic Science International: Genetics

Research paper

Analysis of the South Australian Aboriginal population using the Global 600k Nano accuracy test

Catherine Hedges¹, Charles Yelland¹, Kelly HRF, Andrew Hooper²

¹Police Forensic Science Laboratory, Adelaide, SA, Australia; ²South Australian Police, Adelaide, SA, Australia

HGG Advances COMMENTARY

Community partnerships are fundamental to ethical ancient DNA research

Kenneth Broome,^{1,2*} Laura A. Moravcsik,³ Juan Manuel Aguilera,⁴ Oliva C. Baker,^{1,5} Craig Calver,⁶ Mariana Elena Corcuera,⁷ Daniel J. Gnanapavan,⁸ Paula J. Hancock,⁹ J. Ryan S. Hill,¹⁰ Mark A. Newman,¹¹ Liora Rose,¹² Sam Liu,¹³ Francisco Vargas-Gil,¹⁴ Harshita A. Vatsava,¹⁵ Jennifer A. Wagner,¹⁶ Joseph W. Vaccaro,¹⁷ and Richard A. Yonker.¹⁸

Summary


The ethics of the scientific study of ancient DNA has been debated in archaeology, forensic genetics, and other scientific fields.

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Importance of Informed Consent

- For the subject, family(ies), community(ies)
- For the research and researcher
- For the laboratory, other agencies, government
- Better design of the project
- Better outcome of the project
- Inclusivity
- Overcoming inequality
- Quality of life
- Doing the “right” thing


- It may take more effort, but the end result will protect all, provide dignity and respect, and ensure use of invaluable data collected!



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