

Who owns your research samples and information?

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Talking Law and Ethics



Property Rights

- Sell or dispose of the property
- Lease or mortgage the property
- Licence the use of parts of the property to other people
- Could use the property as collateral
- An action for theft or damage to the property

R v Kelly [1999] QB 621

- Degree of ‘work and skill’ required
 - ‘the application of skill, such as dissection or preservation techniques for teaching or exhibition purposes’
- Does this also apply to ‘human body parts’ from the living?
- Who has the property rights?

Outcome

- An individual cannot ‘own’ their body or parts of it
 - Unless they exercise ‘work and skill’
- Common law recognised the right of ‘bodily integrity’
 - Consent for removal but not for further use
- Accepted as giving some property rights to those who hold samples or body parts

Benefits of Property Rights

- Can use, transfer, sell or dispose of the samples in a biobank, for example
 - Importance of this for commercial collaborations
 - Funding applications
 - Can use to raise finance
 - Action in trespass and theft
- This happening even though the ‘work and skill’ exception is not clearly defined

Jonathan Yearworth & Ors v North Bristol NHS Trust [2009] EWCA Civ 37

- Court said that the men had a property right in the sperm but they narrowly defined it
- This new right only applies to products of a living human body **intended for use by the persons whose bodies have generated them**
- Court did not consider donated products for use by others, such in the case of research

What are the implications of this decision?

- Hold yourself out as having special skills to store material then have a duty of care
- The obligation arises because the taking of possession involves an assumption of responsibility for the safe keeping of the goods
- Does not apply to tissue donated for research purposes

Overview Summary Cut Map Find Show Chromatograms Help Insert Help Reposition

- 32●SFYAKN...
- 26●SFCYTB
- 28●SFn1r
- pr DA-B3min
- pr DAS.f
- pr DAS.r
- YAKND1F/R
- 27●SFYAKN...
- SFN1R
- SFN1F
- 11●SFn1f
- 28●SF.16SB
- pr 16SBR

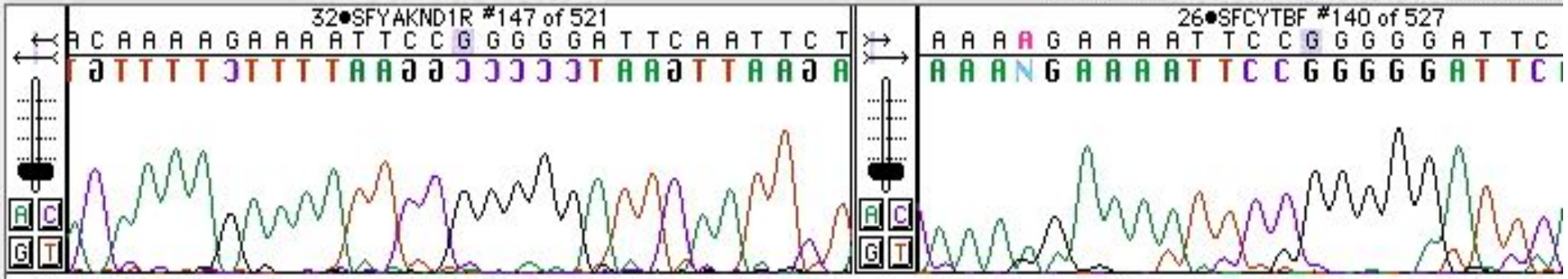
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GAGGAGT AATNGCGCTAGTCCTATCAATCGCCATTTTATTAACTTACCATTCTNTANCAAAAGAAAATTCCGGGGGATTCAATTC'  
GAGGAGT AATTGCGCTAGTCCTATCAATCGCCNTTTTATTAACTTACCATTCTNTAACAAAAGAAAATTCCGGGGGATTCAATTC'
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Displaying 1st frame protein translation.

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|1480 |1490 |1500 |1510 |1520 |1530 |1540 |1550 |1560  
GAGGAGT AATTGCGCTAGTCCTATCAATCGCCATTTTATTAACTTACCATTCTCTAACAAAAGAAAATTCCGGGGGATTCAATTC'  
+ + + +  
GluGluSTPLeuArgSTPSerTyrGlnSerProPheTyrSTPSerTyrHisSerLeuThrLysGluAsnSerGlyGlyPheAsnSer
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23 BPs DNA Fragment - Fri, Oct 29, 1999 15:07:12

Chromatograms from Contig[0090] a



Personal NOT Property Rights

- Data Protection Act 1998
 - Obligations only apply to ‘identifiable’ data of the living
 - ‘explicit consent’ required for sensitive, identifiable information
- Many exemptions for research purposes
 - s.33 Data Protection Act 1998
- Right to privacy – Human Rights Act 1998
 - ‘focuses upon the protection of human autonomy and dignity- the right to control the dissemination of information about one’s life and the right to the esteem and respect of other people’ Lord Hoffman *Campbell v MGN Ltd* [2004] UKHL 22

NO ONE
OWNS THE
DATA

What are Your Obligations?

- Data Protection Act 1998
 - Must comply with the fair processing principles
- Common Law Duty of Confidentiality
- Research Governance frameworks
- Human Tissue Act 2004

Human Tissue Act 2004

- Uses consent to protect donor's interests
 - Extends this from initial removal to subsequent uses
- Need 'appropriate consent' for use except for:
 - Existing holdings
 - Imported collections
 - 'Relevant material' >100 years old
- Not unlawful to analyse DNA from anonymised, existing holding s.46

Human Tissue Act 2004

Tissue from the living may be stored for use and/or used without consent, provided that:

- the research is ethically approved;
- the tissue is anonymised; such that
- the researcher is not in possession of information identifying the person from whose body the material has come and is not likely to come into possession of it.

Requirements for DNA

- Offence to have 'bodily material' with the intent of analysing its DNA without qualifying consent
- Extracted DNA (where no whole cells remain) is not classed as bodily material

In conclusion

- Different requirements for samples and data
- Ownership of a sample raises a number of questions
- No one owns data, but we have different obligations and responsibilities regarding personal and confidential data

Useful websites

- Human Tissue Authority

[http://www.hta.gov.uk/guidance/
codes_of_practice.cfm](http://www.hta.gov.uk/guidance/codes_of_practice.cfm)

- Medical Research Council

<http://www.dt-toolkit.ac.uk/home.cfm>

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