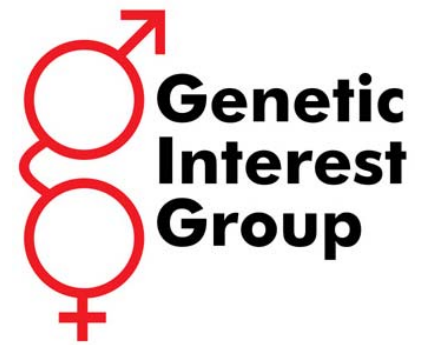


The Impact of the Human Tissue Act on Patient Organisations

Alastair Kent
Director
Genetic Interest Group
London UK

Putting the HTA in context



- Bristol/Alder Hay
- Public Concern
- Lack of Clarity



Regulation

Witch Hunt

Re-opening old wounds

Limited/Incomplete response



Politics



Patients and Research

The Human Tissue Act

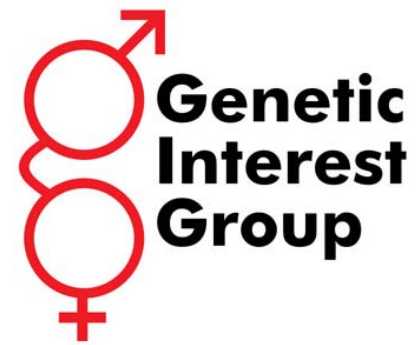


Individuals

Families

Control

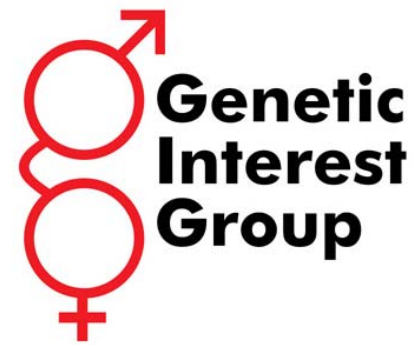
Consent and Trust



- Clinical service; detective work or research
- Consent as a process not an event
- Research is (generally) a good thing

[With thanks to Ponder, Statham, Hallowell, Moon, Richards and Raymond (2007 in Press)]

Family Attitudes



“The rest of the family, insisted that they have the blood test.....I think they are duty bound to provide a blood sample and that is all that is expected of them. I don't want any more, just the blood samples”

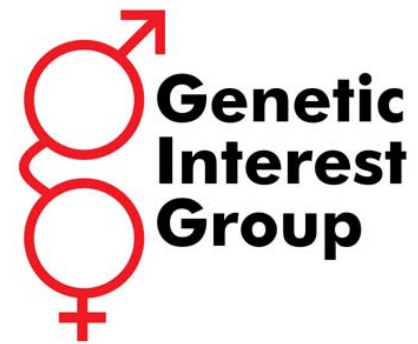
(from Ponder et al 2007)



“...of course, I mean if it’s going to benefit people in years to come. Like there’s no benefit for us apart from the knowledge that..... if they find something out”

(Ponder et al 2007)

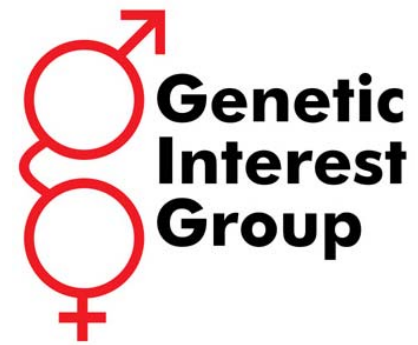
The Human Tissue Act



“Hard cases make bad law”

Not what the Act says but what it is
thought to say!

Interlocking Regulatory Frameworks



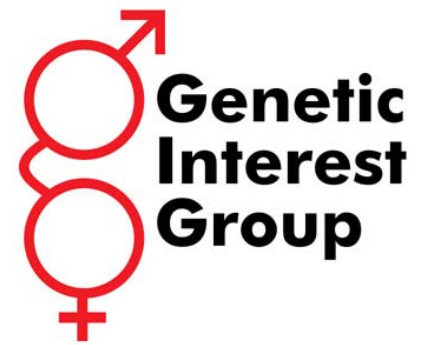
- The HTA
- Data Protection
- Research Ethics Committees
- NHS Trust Ethics Committees
- Clinical Trials Directive
- Common Law
- The Media

Called to Account



- Onora O'Neill
(Reith lectures 2002)

From Trust to “Managerialism”?



- A one way street?
- Can we reverse the direction of travel?



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