



Enabling Grids for E-scienceE

Ethics and biocomputing

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Information Society



- **Some principles**
- **A case study - genetics and DeCODE**
- **Other areas**
 - Patient information
 - Medical imaging
 - Drug trails
 - Data ownership
 - Responsibility - who's?
 - Legal issues
- **Conclusions**



- Right to privacy
- Ownership of data
- Reduction of harm
- Right to information/knowledge
- Informed choice



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- Obviously my genetic information
- My parents information?
- My children's information?
- My grandparent's information?
- Information on my race?
 - Different groups have different rates of different diseases
 - Different groups have different responses to drugs
 - Should I demand that information on my racial group is available?
- **PERSONALISED MEDICINE**



- **DeCODE - Icelandic company building online DB of all resident's genetics since 12th century.**
- **Idea is to provide a resource for researchers in research and industry of a long-term longitudinal study**
- **Supported by Iceland government**
- **Stopped by a legal case and subsequent loss of investor confidence**



- **Licence for Icelandic Health Centre Database**
 - Deceased individuals presumed to have no right to privacy

- **Iceland Supreme Court**
 - Ragnhildur Gudmundsdottir won
 - “Everyone shall enjoy the privacy of his/her life, home and family” - article 71 Icelandic constitution
 - Removing or encrypting the info was not sufficient to prevent identification

- **Other projects**
 - UK & Europe
 - Geno-geography



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- **Several entities involved in treating patients**
- **Messages passed between them**
 - May require message level encryption as well as data encryption
- **Encryption in memory sharing?**
- **Patients may live 20 - 70 years after treatment**
 - Long term support requirement + updating
 - Full history need, + traceability, accountability (who has seen what!)



- **Patient data/records**

- Autocreation of metadata - also has privacy implications
- Autocreation - if wrong can lead to harm/fatalities - who is responsible?

- **Emergencies**

- Pre-emption of resources required!



- **Typical GP interview in UK - 15 mins**

- Must have information in a responsive, timely and robust manner

- **Dynamic 3D Modelling**
 - Very time dependent - surgery!
 - Speed issues with encryption of data & messages
 - Ability to translate and synthesise different formats
 - Encryption/decryption across multiple formats
- **Interactive discussions for image based diagnosis**
 - Must be secure
- **Training sets**
 - May be too small for rare conditions in one institution

- **Sufferers from rare diseases - clinicians may be familiar with most of the individuals through case studies**
 - Can identify individuals from collections of symptoms
 - 1:1,000,000 occurrence - less than 60 in UK, 5 in Scotland, 16 Netherlands
- **Example:**
 - Certain genetic diseases cause diagnostic abnormalities in facial features - difficult to completely anonymise

- **Can bring in the opposite requirement - transparency**
 - Public accountability/privacy
- **Need to support double blind trails**
 - Confidence in results, certification
 - Need full traceability
- **Need to be able to break double blind in emergency**
 - If it becomes clear that there is an unexpected toxic effect/interaction with dose



- **Public databases**
 - VRS
- **Industry/private databases**
- **Old issue in bioinformatics - not completely tested**

- **Algorithms/implementation**
- **Data**
- **Used to treat people**
 - Legal responsibility for life/death
 - In other areas too (design of car brakes?)
- **Compatibilty with clinical practice**
 - Can/does vary between countries

- **Respect heterogeneity of legislation**
- **Technical - ensure support**
- **Sociological - gain support from medical community**

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- **Many issues only appear when you start to share information**
- **Only some of the issues are technical**
 - Technical issues:
 - Interactivity (grid batch system)
 - Responsiveness
 - Reliability
 - Robustness
 - Privacy/security
 - Accountability/provenance
 - Provable algorithms
- **Social issues**
 - Convince clinicians
- **Legal issues**
 - Cross border issues
 - Standardisation/harmonisation

- **So why bother?**
 - Huge market - pharmaceuticals
 - New science that matters to people
 - Requirement for this type of sharing is clear in medicine
 - Provides answers for other communities (finance?)
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