BACKGROUND: FETAL THERAPY

• 1 in 100 babies are born with a severe medical condition
• Huge improvement in outcome if the condition is treated before birth
• New surgical techniques offer safer and more effective treatments
GIFT-SURG

International project to improve the **safety** and **efficacy** of fetal surgery by developing **novel hardware and software** for pre-operative surgical planning and image-guided surgery.
CLINICAL DATA

• Imaging data will guide the development, testing and evaluation of our software
• We will collect data from three hospitals in UK and Belgium
• ~1000 patients, ~1 million images
• Sensitive data – must protect patient confidentiality
• Data sharing must not be a burden to the clinician
GIFT-CLOUD

• Data sharing and collaboration platform
• Extensible system linking three hospitals and two universities
• Simplifies data anonymisation and upload
• Direct upload from hospital systems
• Comply with legal and institutional requirements for data collection and sharing
• Groups data by subject while preserving anonymity
• API for integration with analysis software
Secure storage of anonymised data

One-click anonymise & upload

Access anonymised data via web and GIFT-Surg software
Protecting patient confidentiality

- We do not store identifiable patient data
  Data is anonymised before uploading.
  Patient name, date of birth etc. are removed from the images. This information does not leave the hospital.

- We store our images on a secure server at UCL
  Access is controlled by username and password
  Access is IP-restricted to approved locations and computers.
  All data transfer is encrypted

- We follow NHS and government regulations and guidelines for patient confidentiality and data protection
ANONYMISATION

• Metadata anonymisation
  • Hash patient ID, study UID, series UID
  • Replace patient name with arbitrary identifier
  • Remove DOB, accession number, ...
  • Remove private DICOM fields

• Some metadata not removed – risk assessment
  • e.g. series and study descriptions

• Ultrasound pixel data may contain burnt-in annotations
  • Remove through template matching mechanism – specific to scanner model and image format
### Technical issues
- Anonymisation
- Encryption
- Security of data server

### Legal issues
- Data protection act
- Common law duty of confidentiality
- Data sharing agreements

### Institutional regulation
- Information governance
- Caldicott guardians
- Data protection coordinators
- Ethical review boards

### Perception and risk limitation
- Patient and public advisory group
- Best practices
- Audit trail

### Sensitive data
THANKS