DATA SHARING WITH GIFT-CLOUD

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UCLPartners
Academic Health Science Partnership
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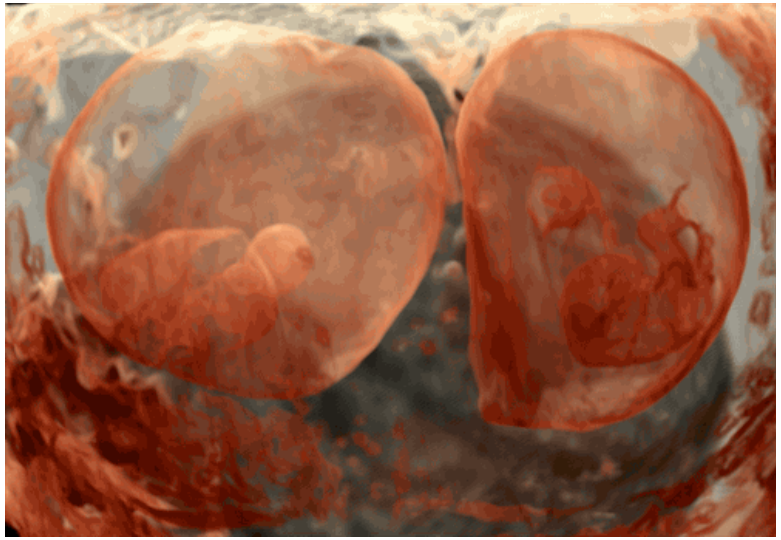
Supported by wellcome trust
EPSRC
Engineering and Physical Sciences Research Council

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

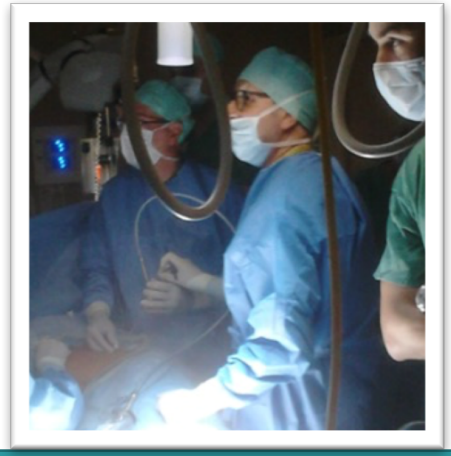
International project to improve the **safety** and **efficacy** of fetal surgery by developing **novel hardware and software** for pre-operative surgical planning and image-guided surgery

Integrated platform

Imaging devices
Actuation devices
Image computing
Software

Accurate information

Bespoke instruments



Reduced risk

Improved outcome

Expressed or latent need – feedback – co-development

Researchers

Clinicians

Patients

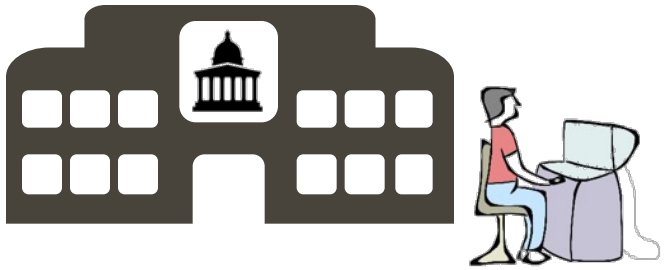
CLINICAL DATA

- 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, ~1million 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

UCL



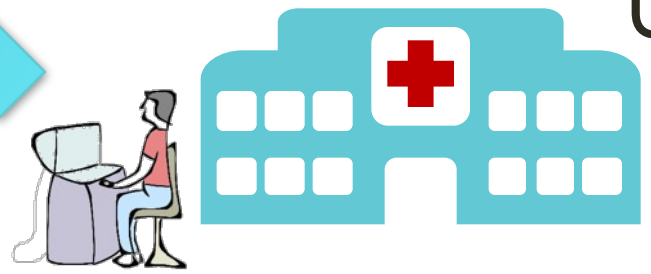
Access anonymised data via web and GIFT-Surg software

KUL

Secure storage of anonymised data

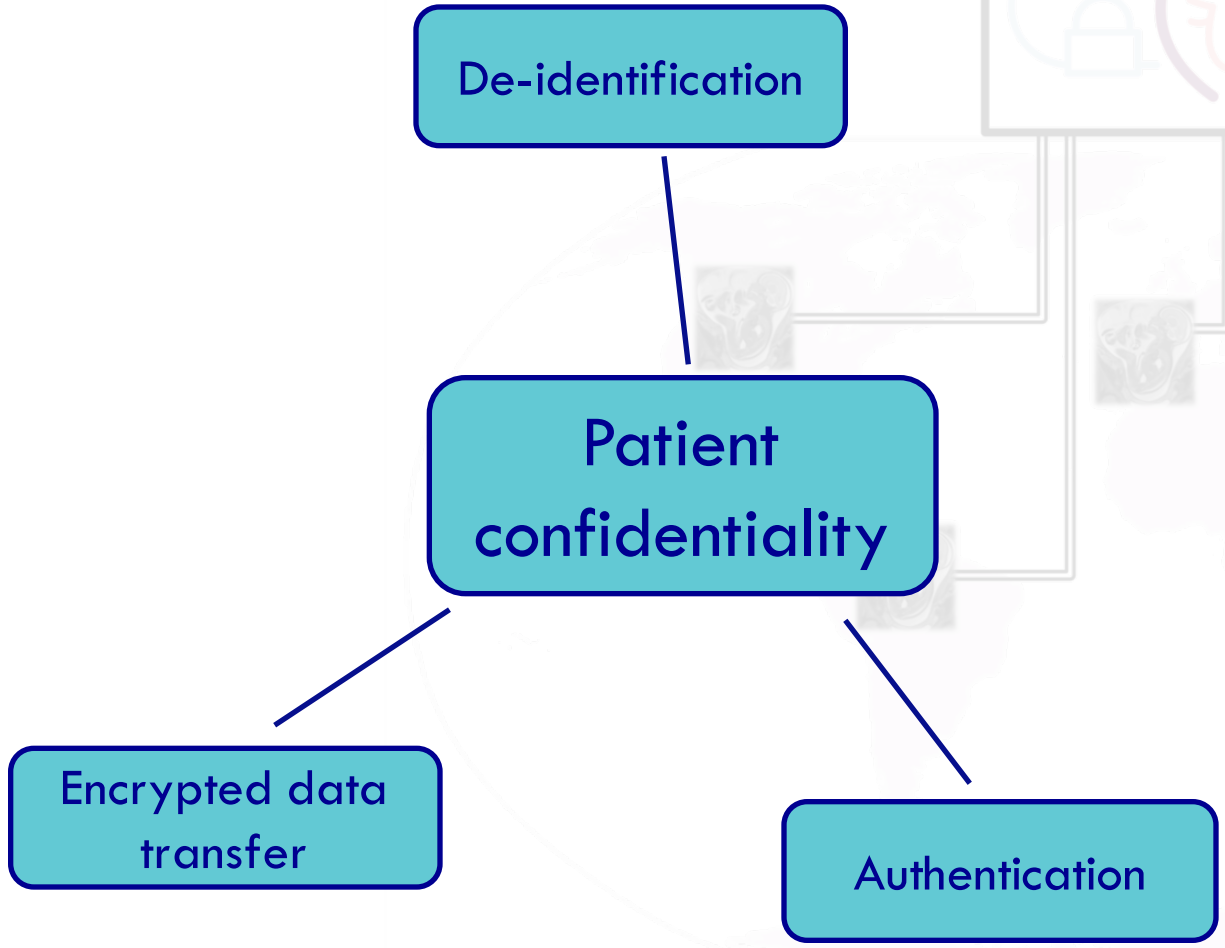
UCLH

One-click anonymise & upload



UZL

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 descritions
- 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

Sensitive data

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

THANKS

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www.gift-surg.ac.uk