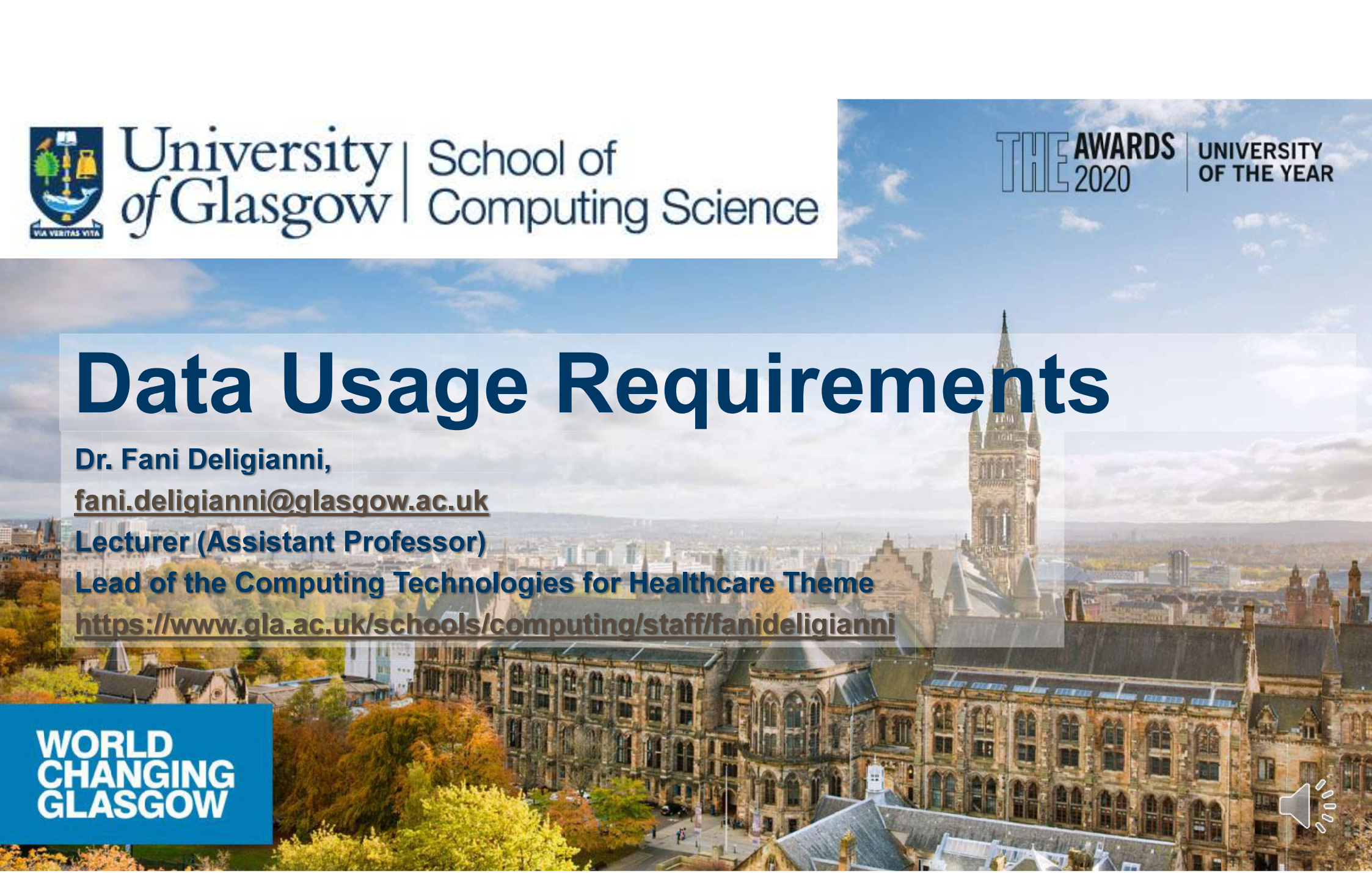
University of Glasgow | School of Computing Science

THE AWARDS 2020 | UNIVERSITY OF THE YEAR

Data Usage Requirements

Dr. Fani Deligianni,
fani.deligianni@glasgow.ac.uk
Lecturer (Assistant Professor)
Lead of the Computing Technologies for Healthcare Theme
https://www.gla.ac.uk/schools/computing/staff/fanideligianni



Data Usage Requirements - MIMIC

- ‘Although de-identified, the datasets described herein contain detailed information regarding the clinical care of patients, and as such it must be treated with appropriate care and respect.’
- The researcher must complete a course in protecting human research participants according to Health Insurance Portability and Accountability Act (HIPAA) requirements via:
  Collaborative Institutional Training Initiative
- The researcher must sign a data use agreement, which outlines appropriate data usage and security standards, and forbids efforts to identify individual patients.

Collaborative Institutional Training Initiative

- Defining Research with Human Subjects
- Privacy and Confidentiality
- Assessing Risk
- Research with Children
- International Research
- History and Ethical Principles
- Regulations and Process
- SBR Methodologies in Biomedical Research
- Genetics Research
- Records-Based Research
- Population in Research Requiring Additional Considerations and/or protections
- HIPPA and Human Subjects Research
- Conflicts of Interest in Research Involving Human Subjects

The Belmont Report

- The boundaries between biomedical and behavioral research and the accepted and routine practice of medicine
- The role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects
- Appropriate guidelines for the selection of human subjects for participation in such research
- The nature and definition of informed consent in various research settings

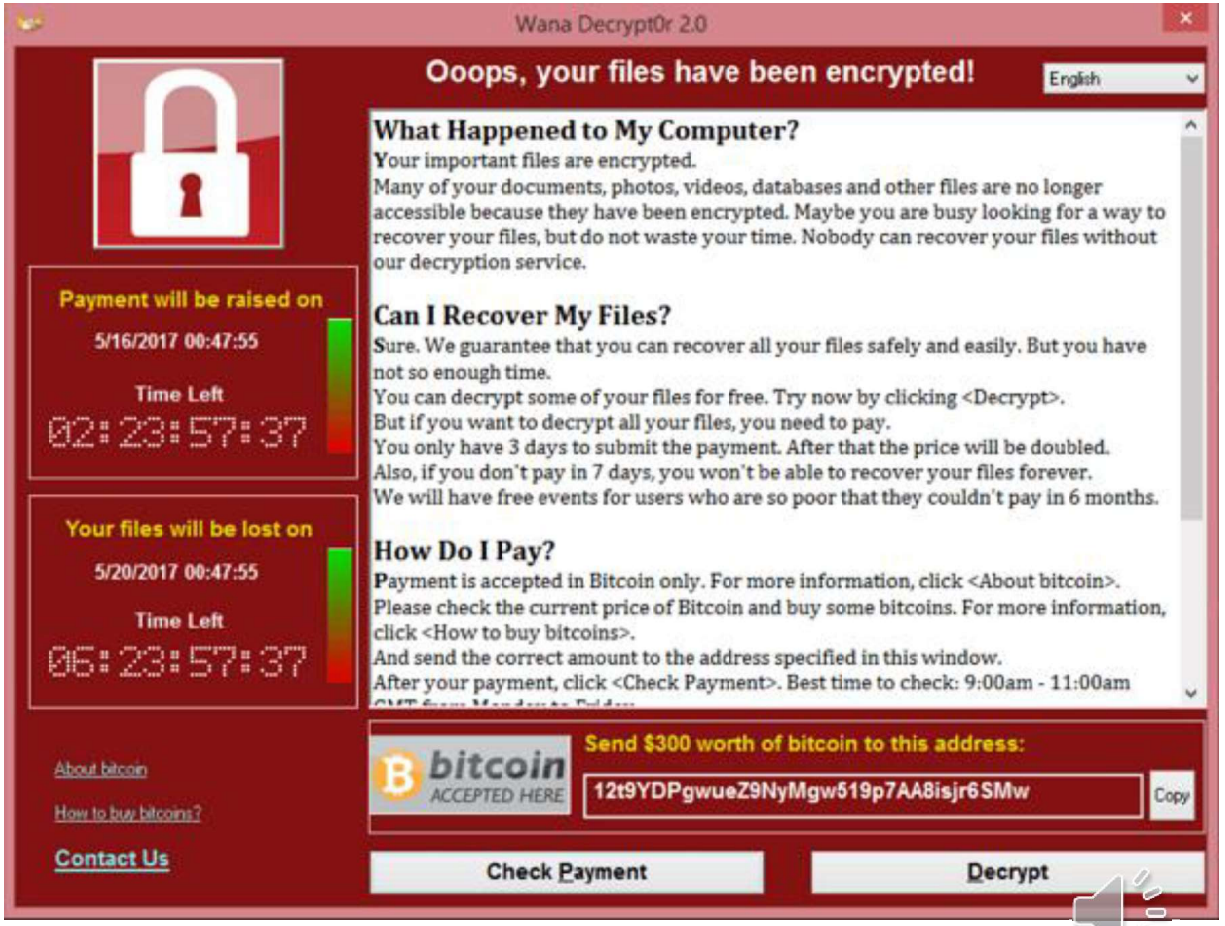
Security

AS WITH ANY ELECTRONIC DATA, IT CAN BE HACKED AND SHARED MALICIOUSLY

PATIENT DATA MUST BE PROPERLY SECURED, ESPECIALLY DUE TO THE EXTREMELY SENSITIVE NATURE OF MEDICAL DATA

WannaCry (2017)

- A ransomware crypto worm called WannaCry was released
- The NHS was affected severely
- The worm exploited a vulnerability in systems using old outdated software
- One third of hospital trusts and 8% of GPs were affected



https://en.wikipedia.org/wiki/WannaCry_ransomware_attack

WannaCry (2017) – The Aftermath

- Across the three days, an estimated 19,000 medical appointments in NHS England were cancelled
- Although NHS Digital has reported it “believes no patient data was compromised or stolen”, this has not been proven
- The Department of Health and Social Care has estimated that WannaCry cost the NHS £20 million during the attack and £72 million in the aftermath, totaling £92 million

Data Inaccuracies

Article 5(1d) of GDPR states that data should be

"accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay"

- Concerns have been made about the accuracy of data stored in EHRs
- Due in part to unfriendly interfaces designed without considering the users, ie. clinicians
- And exacerbated by the misconception that EHRs are "clean" and "accurate"

Who Owns Your Data?

- Every country has different laws about who owns the medical records
- Patients have legal privacy, security and accuracy rights
- In the UK and EU, General Data Protection Regulation (GDPR) and the Data Protection Act of 2018 protects patient data

Summary

- The Collaborative Institutional Training Initiative Course should be taken online before any use of MIMIC dataset
- This is an official comprehensive guide on ethics and principles behind research that involves ‘human subjects’
- **Please, complete the ethics to be able to continue this course**

References

- Johnson et al. ‘MIMIC-III, a freely accessible critical care database’, Scientific Data, 2016.
- The Belmont Report, Ethical Principles and Guidelines for the Protection of Human Subjects of Research, https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html