University of Leeds

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The balancing act between Innovation and Regulation: Theory and Practice

Subhajit Basu





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Vice-Chair BILETA

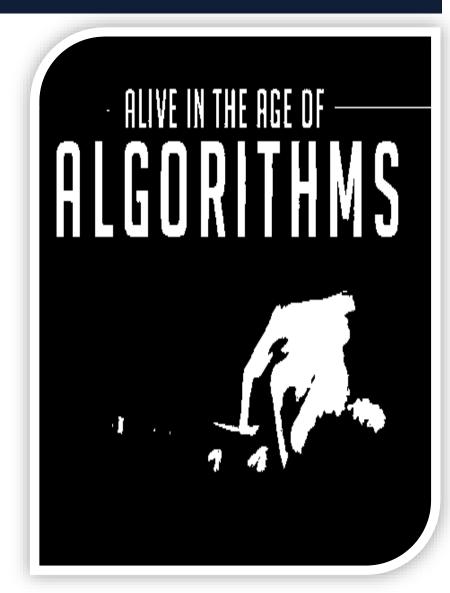
Associate Professor

Email:s.basu@leeds.ac.uk



Data-driven Innovation and Building the data Economy

- "Big data" is becoming a core asset in the economy, fostering new industries, processes and products and creating significant competitive advantages.
- Across every field data is the creed; the answer to everything.



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- Data-driven Innovation: The "problem" of data
 - Challenges related to governance and policy
 - Challenges related to public understanding and public trust
 - Questions about privacy, consent, data ownership and transparency



Data-driven Innovation: Google DeepMind and Healthcare Data: A Case Study

- DeepMind has been given access to the healthcare data of up to 1.6 million patients from three hospitals run by a major London NHS trust
- DeepMind will launch "Streams" (an app for identifying acute kidney injury). It will trigger mobile alerts when a patient's vital signs or blood results are flagged as abnormal.
- NHS has used a loophole around "implied consent", NHS does not require patient "consent" for direct care.
- UK's data protection watchdog, the ICO, is investigating complaints about the "Streams" app



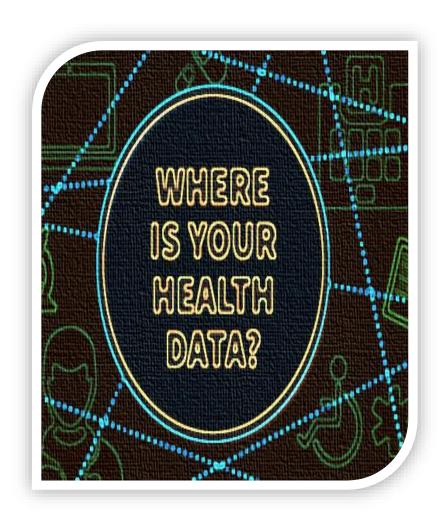
DeepMind data-driven innovation:

- Consent or collect-it-all: did the patients sign up for this?
- Transparency and fairness?
- Can Google/DeepMind be trusted?
- What's in it for Google, for DeepMind?





- What are the most important ethical and legal challenges raised by AI in healthcare?
- Who does (and can) own data anyway, and on what basis?
- How do we ensure the rights of patients, indeed of all individuals, are safeguarded?



- Does current legal framework on data protection takes into account the reality characterised by the development of data-driven innovation in healthcare?
- What is the role that technology can play to ensure that datadriven innovation advances in an optimal way, particularly in the context of the privacy of the healthcare data?



The (missing?) "balancing act":

- Do we need new regulatory framework to protect privacy while at the same time advancing medical research and healthcare?
- Do we need new ethical standards for the private sector if they operate in healthcare context?





The (missing?) "balancing act": Public understanding and concerns

- What about the need of public benefits from research/deals or is it just about commercial gains?
- How can we use the increasing amounts of data in society for public good and with public support?



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- Our aim has been to encourage and empower patients to make informed choices about sharing their health data.
- To provoke new visions for sharing of healthcare data. We framed such discussion through an exploration of the changing concept of 'privacy' and 'patient control' in healthcare information management.

