The balancing act between Innovation and Regulation: Theory and Practice

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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.
• 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 data-driven 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?
• 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.