Beyond the present: Privacy and Personalised Medicine

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Privacy and Personalised Medicine

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Data has become a vital component in healthcare:

- (the secret of life) Most of us are not ‘Average’
- Wearable devices continuously collect patient health care data
- Health care as we know it is primarily reactive in nature - the medical community is trying to shift from reactive care to proactive and preventive care
- P4 medicine (personalized, predictive, preventive and participatory)
• Is personalised medicine inherently discriminatory?

• Ever-finer distinctions among individuals, could play a part in ‘genetic discrimination’

• Huntington’s disease - real fears of discrimination and stigma, worries of people using false names

• Pharmaceutical companies could invest in products for the most valuable markets, not the medical needs of those who suffer from the most prevalent diseases. Hence the fear of a new kind of racial segmentation of medicine

• Insurance companies have been seen as having an inherent conflict of interest in seeking and obtaining patient’s genetic test results—providing care vs. saving costs
“All about me”

• if I am in a low risk category, should I pay higher taxes for the entirely predictable illnesses of those at high risk—or should I opt out and insure myself, taking advantage of low rates on account of my genetic good fortune.

• if I know, or could know, that I am at high risk, should I disclose this information or disguise it—leaving others to take responsibility for the costs of my failure to disclose?

“Patients Like Me”
Is **privacy** the **price** of personalised medicine?

- A genome constitutes ‘**de-identified**’ information
- **Re-identification** is increasingly possible, if not probable
- **Google DeepMind and Royal Free Hospital**
  
  “The renal team were there before the team looking after the patients knew anything was wrong. I’m sure that almost none of the patients would mind their data being used for that.”

- In August organisations including Diabetes UK, Arthritis Research UK, Cancer Research UK, the British Heart Foundation, and the Wellcome Trust launched an advertising campaign about the importance of sharing data from patient records with researcher
Sharing data can lead to new knowledge, but what about regulation?

- General Data Protection Regulation and the Data Protection Bill 2017-19
- Sensitive personal data, called 'special categories of personal data' in GDPR

The Bill is also designed to create new criminal offences of:

- intentionally or recklessly re-identifying individuals from anonymised or pseudonymised data
Personalised Medicine: Conclusion

• NHS **belongs to the people**- It works at the **limit of science** - bringing the highest levels of human knowledge and skill to save lives and improve health

• An **informed**, engaged and **empowered** patient

• Regulation should be premised on the basis that **one breach of privacy is one too many**

• Unnecessarily complex data protection rules impede progress.