

It's not about the technology: legal and ethical challenges in delivering citizen-focused e-Health services

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1. Introduction

- **Focus on patient privacy and confidentiality**
 - **In context of NPfIT:**
 - **A broadband spine connecting all of those working in the NHS**
 - **An electronic patient record (to be managed by the NHS Care Records Service)**
 - **Booked admissions (Choose and Book)**
 - **Electronic prescribing**
 - **Top down/bottom up**
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2. e-Health and its impact on business processes

- **Moving from an analogue, paper based world to networked health advice and services**
- **Communicating from one to many**
- **Having information available whenever and whenever it is needed**
- **Improved standards of care for patients**
- **Creating and deploying structures from the top/down**

3. e-Health – the legal context

Traditionally:

- You can do whatever you like unless there is a law against it. Approach been based on pragmatism
- Compare jargon about "citizen empowerment" and Englishman's status as subject to Her Majesty

Present approach:

- Data Protection Act 1998
- Human Rights Act 1998
- Freedom of Information Act 2000

4. Data Protection Act 1998 - some further detail

- **Personal data must be processed in accordance with the eight principles of the Act.**
- **It must be processed “fairly and lawfully”**
- **If sensitive personal data, there must be:**
 - **Explicit consent to the processing of the personal data; and**
 - **The processing is necessary for medical purposes and is undertaken by health professional (or person who owes equivalent duty of confidentiality)**

4. Data Protection Act 1998

- some further detail (Continued)

An individual is entitled to stop or restrict data processing on the ground that:

- **The processing is likely to cause substantial damage or substantial distress to him or to another, and**
- **That damage or distress is or would be unwarranted**

Does or should this provision give any meaningful rights to a patient to opt out of some or all of his health record being placed on the electronic spine by the NHS?

5. Privacy and confidentiality

- **Human Rights Act 1998:**
 - **Respect for his private and family life**
 - **Except for the protection of health**
- **Common law obligation to keep patient consultations confidential.**

6. The law just gets in the way

- We have a beautiful idea
- The idea is being implemented
- There has been little involvement or regard for patients
- Positions are becoming polarised

7. Moving towards a solution?

- **Winning hearts and minds**
- **Talk to the medics**
- **Promote a debate with the public**
- **Discourage driving parties to extreme positions**
- **Emphasise the need for pragmatism**
- **Good news is coming**

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