



Department  
of Health

# Data sharing and consent in England

**Katie Farrington, Director of Digital and Data Policy**

# Challenges on Data Security

- Threat is growing as healthcare becomes an ever increasing target
- Thousands of attacks on the NHS IT Network an hour
- Capabilities vary widely – from good to bad
- Challenge is achieving consistency across the NHS, in the key areas of people, processes and technology



# Challenges on consent and public trust

- Elements of the public and media remain concerned and vocal
- Ongoing dialogue is needed to rebuild trust
- Essential people have the right to opt out and know what is happening with their data



The image shows the front page of the Daily Mail newspaper. At the top, the masthead reads "Daily Mail" in a large, stylized font, with a royal coat of arms logo in the center. Below the masthead, the date "WEDNESDAY, MAY 4, 2016" and the website "www.dailymail.co.uk" are visible. The main headline is "The incomparable Cainer and why only fools (and men) mock horoscopes" by Sarah Vine, on page 15. A secondary headline reads "PLUS: HIS FORECASTS FOR A NEW COSMIC SPECTACULAR" on pages 30-31. The largest headline is "GOOGLE HANDED PATIENTS' FILES" in a very large, bold, black font. Below this, a sub-headline states "Up to 1.6m private records passed on without permission in NHS deal with internet giant". The article is by Sophie Borland, Health Editor. The text of the article is partially visible, mentioning that up to 1.6 million patients had their private medical files passed on to Google without their permission. A photograph of Jamie Vardy and his fiancée Becky Nicholson is featured, with a headline "Star of football's fairytale hits £5m jackpot". The caption below the photo says "Aiming high: Leicester's Jamie Vardy, with fiancée Becky Nicholson, has won a £20,000 a week rise". The page number "PAGE 5" is in the bottom right corner.

**Daily Mail**  
WEDNESDAY, MAY 4, 2016 www.dailymail.co.uk DAILY NEWSPAPER OF THE YEAR 65p

**The incomparable Cainer and why only fools (and men) mock horoscopes**  
SARAH VINE PAGE 15

**PLUS: HIS FORECASTS FOR A NEW COSMIC SPECTACULAR** PAGES 30-31

# GOOGLE HANDED PATIENTS' FILES

**Up to 1.6m private records passed on without permission in NHS deal with internet giant**

By Sophie Borland  
Health Editor

UP TO 1.6 million patients have had their private medical files passed on to Google without their permission. The internet giant was given the data by one of the largest NHS trusts to develop an app to monitor possible kidney failure. The encrypted information includes the names and medical histories of every patient who had stayed in hospital overnight or attended A&E in the past five years. None of the patients was told beforehand and the revelation has exposed the ease with which private companies can obtain highly sensitive medical information without consent. Experts say the deal between Google and the Royal Free NHS Trust could set a precedent for patient data to be routinely passed on to private firms. The Royal Free insisted it did not sell the files to Google and no money changed hands. The trust, which includes three London hospitals, and Google say the data is encrypted, will be processed by only a computer programme, and there is no chance of it being leaked online. Trust managers approached Google to develop the app and then handed over the patient files after signing an information-sharing agreement last year. Neither the trust nor Google needed to ask patients' permission beforehand because the NHS is obliged to pass

**Star of football's fairytale hits £5m jackpot**

Aiming high: Leicester's Jamie Vardy, with fiancée Becky Nicholson, has won a £20,000 a week rise

PAGE 5

# The National Data Guardian's review into Data Security and Consent

- In 2015 the Secretary of State for Health commissioned Dame Fiona Caldicott to contribute to a review of data security being carried out by the Care Quality Commission, to:
  - develop new data security standards that can be applied to all health and care organisations
  - with CQC, develop a method of testing compliance with the new standards; and
  - propose a new consent / opt-out model for data sharing, enabling people to make informed decisions about how personal data about them is used.

# Opportunities

- Enormous potential for data to be used to drive improvements in health and care, and growth in the economy
- UK Government is committed to growing this industry - want to be an attractive place for investment across digital health
- Government is investing £4.2 billion during this Parliament to support the NHS to be paperless by 2020
- Progress depends on maintaining public and professional trust
  - Secure systems and processes
  - Informed public with strong rights around how their data is used