

# 13. Our personal health data must not be sold

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Health data is private and sensitive. **Our personal information is becoming a new form of corporate asset** worth £10 billion if powerful Big Tech companies gain a stranglehold on that data without safeguards. NHS data is important for research for the public good. Management of our data by the NHS should be founded on public trust. It must not be exploited for profit. The NHS is increasingly dependent on digital technologies. More decisions about our healthcare are based on computer-generated rules (algorithms) that are closed to challenge. Human interaction in clinical decision-making is becoming marginalised with worrying implications for patients and staff.

## WHAT ARE THE FACTS?

- **The NHS holds the single biggest health data set in the world**
- The £480 million contract for the data platform controlling this has been awarded to Palantir the US spy tech and battle tech company
- Our personal health and genetic data are increasingly detailed and intimate in nature; yet the Government is set to allow the private sector to exploit this data
- **Governments have failed to invest in NHS IT infrastructure**; the NHS is left heavily dependent on tech companies to control data platforms, data analysis and processing
- This allows corporate access to our sensitive information and Big Tech can shape decisions on healthcare developments and treatment to serve its own agenda
- In the US, wealthy pharma companies have illegally used IT algorithms to maximise profit from drug prescribing
- **Our right to opt out of our data being used for purposes beyond our direct care is at risk**
- Weakened legal protections for our data – Secretary of State can bypass Parliament and impose new legislation unilaterally
- The Information Commissioner's Office (data watchdog) is no longer independent of government and must consider business interests and economic growth when considering data safeguards

## WHAT MUST HAPPEN NOW?

- People must have the right to know who is using our data, how and for what purpose
- Governance of patient health data through legally backed, independent bodies that can restore trust
- Clarity about consent, and a right to opt out of our data being accessed
- Citizens' rights and the public good must be paramount – above the interests of commerce

- Comprehensive and meaningful patient involvement on how NHS data is used
- State-funded investment allowing the NHS to develop relevant technologies and staff training and reduce its dependence on the private sector