

Introductory meeting with Tim Kelsey, 10 February 2015

Present: Tim Kelsey (National Director of Patients and Information), John Pullinger (National Statistician) and Emily Greenslade (APS to the National Statistician)

Tim and John gave brief overviews of their current and previous roles.

Tim talked about the Care Act and the Confidentiality Advisory Group (CAG). The regulations for CAG will be laid before Parliament after the election. The Care Act permits patient data to be used only for health and care benefit – it explicitly excludes purely commercial uses, including insurance purposes.

The government has a new patient right to opt-out of data uses other than direct care and there is a need to properly explain to people how their data will be used. There is a commitment to have a fully consent based system for health by 2020.

Care.data has been re-designed since it was first launched in 2014 in collaboration with national and local stakeholders, clinicians and patients.

There was a discussion about how both organisations could work together around data sharing and privacy, specifically how to hold a proper debate about data and understanding the consequences of withholding consent. Tim offered to provide case studies from the United States.

A suggestion was to have a co-funded round-table/forum event involving key players like Reform and the Institute for Government after the general election.

John talked about the Data Citizen Project proposal from Rewired State as another possible area for working together.

Tim invited John to attend the National Information Board which Tim chairs. This board includes all arms length bodies.

Actions:

- Tim to provide dates of the National Information Board for John to attend
- Tim to provide Dame Fiona Caldicott's report on care.data, Personalised Health Care 2020 and case studies
- John to speak to contacts at the Institute for Government to see if there is an appetite for hosting a forum event