

Project Aims

In October 2014 the national **care.data** programme had been delayed by over a year. Board meeting minutes and its cost-benefit plan were unpublished. There was little information in the public domain.

This FOI request aimed to obtain transparency of all due diligence and decision making, with a focus on its measurable costs and benefits. This was to enable public scrutiny in the public interest, and increase public understanding of the plans.

The need for this was based on 3 key concerns:

- 1) **Past national NHS IT programme failings** (NPfIT, Connecting for Health, Healthspace), their associated costs in monetary terms, and risk of harm to professional and public confidence.
- 2) **Budget spend and forecast**: the current NHS financial position and expectations outlined by NHS England until 2020 mean that any programme failing to deliver, should reasonably be able to justify its costs against other plans.
- 3) **Governance**: delays were mounting without transparency of responsibility or oversight.

At a time when trust in the programme was vital for success it should have welcomed scrutiny and transparency of its costs, time requirements, and ongoing future financial implications.

In a 2011 survey carried out on behalf of the Information Commissioner's Office, 81% of public bodies questioned agreed that the Act had increased the public's trust in their organisation.

Yet in this case NHS England declined the request under Section 22 exemption.

In October 2014 when the request was made, there was no planned publication date for the minutes.

The request

"To provide copies of the minutes and materials from the care.data Programme Board held in 2014 to date: agenda, minutes, meeting dates, attendees list, and any documents used at each meeting."

Project Outcome

Minutes and materials were released in August 2015.

Some items were published on NHS England's care.data website after this. However some materials are still only available on whatdotheyknow.com.

These reveal the programme:

- had no financial or measurable cost-benefit business case in place.
- plans for further expansions of data collection.
- at the May 2014 meeting in which the care.data programme board was reconstituted, the secretariat was instructed not to take minutes.

The narrative is clear of the refusal to change programme substance in private, despite public acknowledgment at engagement exercises of the professional & public calls for meaningful change to secure public trust and move the programme forward.

In over sixty 2013-2015 published papers from the care.data programme board meetings there are few redactions and only one was made on the basis of commercial confidence section 43 exemption.

Yet in January 2015 the Programme Board meeting was separated into two sessions.

"The second session will be a private session where items that are commercial in confidence will be discussed and the supporting agenda, papers and minutes of this session will not be made available on the care.data programme website."

The need for any private session is unclear. Nothing disclosed could have been obviously adversely affected by transparency and if other views had been sought may have resulted in better policy making and public and professional trust.

When in December 2014 NHS England confirmed it held the information it withheld it under Section 22. I was told this information was to be published soon:

"we feel that it is best and reasonable to keep to this timeframe rather than disclose earlier where error or duplication may occur."

However publication did not happen until ICO served an Information Notice to NHS England in July 2015.

FOI request and results: https://www.whatdotheyknow.com/request/caredata_programme_board_minutes The business case is missing: http://bit.ly/1SCvVAC and care.data delays continue: http://bit.ly/1NBCweC