



North Devon Council

Report Date: 2 August 2021
Topic: **NHS Data Opt-out**
Report by: Environment Lead

1. INTRODUCTION

- 1.1. NHS Digital is planning to create a central database to hold the complete history of our GP records of care.
- 1.2. The data held in our GP records is the richest source of continuous population-wide health information in the world.
- 1.3. The NHS already has the most comprehensive, summarised, health data in the world which is invaluable for research and planning.
- 1.4. The data held in our GP records belongs to us as individuals, not to the GP or anyone else.
- 1.5. In the UK we operate a principle of informed consent for use of our data, and not an assumed consent from which we can opt out.

2. RECOMMENDATIONS

- 2.1 To write to our MP and ask her not to support NHS Digital's plans for a central GP databank and to oppose any moves to water down our personal privacy protections.
- 2.2. To recommend that our residents opt out of their full GP history being uploaded to a central database.

3. REASONS FOR RECOMMENDATIONS

- 3.1. To support the principle of informed consent.
- 3.2. To protect our personal data from uses with which we may disagree and over which we have no control.

4. REPORT

- 4.1. Health data is a multi-trillion dollar global industry, and the data held in our GP records is the richest source of continuous population-wide health information in the world.
- 4.2. Sharing of data has become part of our way of life but it is important to bear in mind that we have a right to expect that our personal data will be protected and we have data protection laws specifying how and when data may be used.

- 4.3. We each own our own personal data. The organisation with which we share it does not own it.
- 4.4. Consent to use of our data should be given by a clear, affirmative act (informed consent), and not assumed by silence, pre-ticked boxes, or inactivity. As such, all consent to use our personal data should be opt-in, and never opt-out.
- 4.5. In June NHS Digital published plans to set up a central database to hold our individual GP health history. This was with little notice to opt out, virtually no national advertising, no guarantee that the data is anonymised, and with retention of all data taken even if the opt out was exercised later. Many people would not have known anything about this.
- 4.6. As a result of public pressure NHS Digital have changed the rules about when to upload data and have said that they will now remove any data if an individual chooses to opt out later.
- 4.7. GP health data, in summary form with no personal identification, is already extracted for the purposes of national research and planning.
- 4.8. NHS Digital say they are responding to the intense demand from across a wide range of interested parties, for general practice data to be shared in support of vital planning and research for Covid 19. These are some of the wide range of interested parties who had/have access to Covid 19 data: Palantir, Amazon, Google, Faculty.
- 4.9. GP data would be of particular interest to the likes of Optum and Centene, the latter, which currently owns a chain of GPs and a share in the digital GP at Hand, describing itself in the US as primarily a data company which happens to deal in health, and pharmaceutical companies.
- 4.10. The concern about this action is that it will remove our legal data protections.
- 4.11. A central database has wide-ranging implications for future trade deals.

5. RESOURCE IMPLICATIONS

- 5.1. None

6. EQUALITIES ASSESSMENT

- 6.1. The government should have done an impact assessment and it is likely that those with least access to tech will be unlikely to hear about this and will not have the means to opt out

7. STATEMENT OF CONFIDENTIALITY

- 7.1. This report contains no confidential information or exempt information under the provisions of Schedule 12A of 1972 Act.



8. BACKGROUND PAPERS

8.1 After public pressure this was released on 19th July: [New plans to increase protection and strengthen security for GP data collection programme - NHS Digital](#)

8.2. Will our data become a lucrative commodity?: [NHS data sale 'an invasion of privacy', campaigners say - BBC News](#)