

Day 1: Pre-jury questionnaire

Please complete every question and then press "Done"

* What is your juror number (on the inside cover of your binder)?

* What are your initials?

* 1. Which of the following uses of NHS data about patients (with identifiers like name and address removed) are acceptable?

Answer either "yes, acceptable", "No, unacceptable" or "I'm unsure" to the four uses of data below.

a. NHS staff working for Salford Royal Hospital get data from ambulances and hospitals. The purpose is to do research to help paramedics get better at spotting the signs of people who have had a stroke.

* b. University researchers in Leeds get data from hospitals, GPs and social care about frail elderly patients. The purpose is to help GPs identify individual patients needing extra care and follow up.

* c. University researchers in Liverpool get data from hospitals and GPs. The purpose is to provide information to doctors, nurses and ambulance staff about how to give more appropriate care to people suffering from alcohol-related problems.

* d. University researchers in Newcastle get data from hospital, GP and local authority records. The purpose is to plan future demand for A&E services and meet the needs of special groups (e.g. people with dementia).

Do you have any comments about your answers to 1a, 1b, 1c or 1d?

* 2. Which of the following potential uses of NHS data about patients are acceptable?

Answer either "yes, acceptable", "No, unacceptable" or "I'm unsure" to the four uses of data below.

a. A pharmaceutical company requests general practice data about patients (with identifiers like name and address removed) including prescriptions, blood glucose measurements, and complications of diabetes patients. The purpose is to understand better what prescribing patterns get the best results for patients.

* b. A large computer software company seeks data about patients from hospital and general practices (with identifiers like name and address removed) including patient symptoms, diagnoses and outcomes. The purpose is to enable its intelligent software to "learn" and so be used to aid future diagnosis of sepsis, a life-threatening condition.

* c. A developer of an app, designed for a wearable device like a fitbit that tracks a person's activity and measures key health indicators like blood pressure, seeks hospital data about patients (with identifiers like name and address removed). The purpose is to enable them to design the app to suggest safe fitness regimes tailored to each individual's capability and characteristics (age, weight etc.).

* d. A health club chain seeks aggregated data (i.e. total numbers of patients) comparing levels of exercise, smoking history, alcohol consumption, body mass index, blood pressure for people who have had a heart attack with those who have not had a heart attack. The purpose is to understand and identify the type of club members who are most at risk of a heart attack and monitor them.

Do you have any comments about your answers to 2a, 2b, 2c or 2d?

* 3. As you may know, different government departments and services collect data about individuals, for example your tax records and health records. People have different views on how much of this information should be shared within government. Data sharing can bring benefits, such as finding more effective medical treatments, using information about local communities to plan local schools or roads etc. But some people worry that data sharing will be a risk to their privacy and security, by linking different types of data together and potentially allowing them to be identified. Overall, which of the following statements is closest to your view?

a) "We should share all the data we can because it benefits the services and me – as long as I can opt out if I choose"

b) "We should not share data as the risks to people's privacy and security outweigh the benefits"

- Agree much more with a) than with b)
- Agree a little more with a) than with b)
- Agree equally/ don't agree / don't know
- Agree a little more with b) than with a)
- Agree much more with b) than with a)