

Reference:	FOI.19761.26
Subject:	Patient demographic data
Date of Request:	25 February 2026

Requested:

Please provide responses to each of the questions included in the form at the following link:
<https://app.onlinesurveys.jisc.ac.uk/s/icr/interact-p-survey>

NHS trust details

1. Trust name
2. How many clinical trials are being run at your trust currently?
3. Which type of organisation best describes you?
 - Acute/General hospital trust
 - Specialist trust (e.g. tertiary, cancer)
 - Community health trust
 - Mental health trust
 - Ambulance trust
4. Is your trust a teaching hospital and/or university affiliated? Yes/No
5. How many full-time equivalent (FTE) staff are employed by your trust?
 - <250
 - 250-999
 - 1000-2999
 - 3000-6999
 - 7000+

Demographics

6. What demographic data do you collect for patients being treated at your trust and where is this recorded? (select all that apply)
 - "EPR" refers to Electronic Patient Record, the digital system used to store patient information.
 - "Fields" refer to structured sections in the EPR for entering specific data (e.g., diagnosis codes).
 - "Elsewhere in the EPR" includes free text entries typed by clinicians and healthcare professionals or documents uploaded to the EPR to provide additional detail.
 - a. Ethnicity
 - Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
 - b. Preferred language
 - Not recorded

- Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- c. Religion or belief
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- d. Sexual orientation
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- e. Sex
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- f. Gender
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- g. Marital status
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- h. Caring responsibilities
- Not recorded
 - Specific field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
- i. Employment status
- Not recorded

- Specific field in the EPR
- Elsewhere in the EPR
- Written/hard copy patient notes
- Other hospital system

j. Postcode

- Not recorded
- Specific field in the EPR
- Elsewhere in the EPR
- Written/hard copy patient notes
- Other hospital system

k. Other socioeconomic indicators such as accommodation type or Area Deprivation Index

- Not recorded
- Specific field in the EPR
- Elsewhere in the EPR
- Written/hard copy patient notes
- Other hospital system

7. If you selected 'other hospital system' for any of the categories in the previous question, please specify:

8. Where is demographic information sourced from? (select all that apply)

- New patient registration form
- Existing NHS records
- Referral letter
- Asking the patient directly
- Other (please specify)

9. Is the completeness of this data checked routinely?

- Yes
- No
- Unsure

10. How complete is the data?

- <25%
- 26-50%
- 51-75%
- >75%
- Unsure

11. Please provide any additional information/comments about the completeness of this data:

12. Are you aware of any challenges with the collection of demographic data at your Trust?

Clinical trial participation data

13. Is there a dedicated field in your EPR system that indicates whether a patient was:

- "Fields" refer to structured sections in the Electronic Patient Records (EPR) for entering specific data (e.g., diagnosis codes).

- a. Screened for a clinical trial
 - Yes
 - No
 - Unsure
- b. Eligible for a clinical trial
 - Yes
 - No
 - Unsure
- c. Approached about a clinical trial
 - Yes
 - No
 - Unsure
- d. Declined taking part in a clinical trial
 - Yes
 - No
 - Unsure
- e. Recruited for a clinical trial
 - Yes
 - No
 - Unsure

14. If this data is not recorded in a field of the EPR, is this data recorded elsewhere? Please respond for each category (screened, eligible, approached, declined, recruited):

15. If a patient is ineligible, not approached or declines clinical trial participation, are the reasons why recorded and if so, where? (select all that apply)

- "EPR" refers to Electronic Patient Record, the digital system used to store patient information.
 - "Fields" refer to structured sections in the EPR for entering specific data (e.g., diagnosis codes).
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- a. Ineligible
 - Not recorded
 - Field in the EPR
 - Elsewhere in the EPR
 - Written/hard copy patient notes
 - Other hospital system
 - b. Not approached
 - Not recorded
 - Field in the EPR
 - Elsewhere in the EPR

- Written/hard copy patient notes
- Other hospital system

c. Declines participation

- Not recorded
- Field in the EPR
- Elsewhere in the EPR
- Written/hard copy patient notes
- Other hospital system

16. If you selected 'other hospital system' for any of the categories in the previous question, please specify:

Questions about your internal audit processes

17. Does your trust conduct central audits regarding trial participation at your site?

- Yes
- No
- Unsure

18. Do any departments in your trust conduct internal audits regarding trial participation?

- Yes
- No
- Unsure

19. Please provide any additional information on audit activity including how often they are/have been conducted:

20. Are trial participation rates reviewed in relation to particular demographics, such as ethnicity, sex or age?

- Yes
- No
- Unsure

21. Are you aware of any barriers to trial participation for any underserved groups at your trust?

- "Underserved groups" refers to a group of people who face systemic barriers to accessing or receiving quality healthcare and other services, such as clinical trial participation. They are underserved due to factors like ethnicity, geographic location, age, gender identity, sexual orientation, disability, income, or language, which may result in reduced access and poorer health outcomes.

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested for questions 7 to 12, as it is estimated that the cost of answering your request would exceed the "appropriate limit" as stated in the Freedom of Information Act 2000 and the Data Protection (Appropriate Limit and Fees) Regulations 2004. The "appropriate limit" represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The responsibility of updating the Patient Record with the details requested sits with the 'point of contact' for a patient and every department will have a different procedure for recording this information. Therefore, the UHB would be required to ask every department that has 'patient contact' for their individual processes to be able to identify any information that may fulfil your request, before having to link the information together and break it down to answer each of these 6 questions.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request due to the UHB still requiring contact to be made with each department that has patient contact, to identify any of the information requested.

Under section 16 of the FoIA, the UHB has a duty to provide advice and assistance and provides the remaining information it holds, within Attachment 1.