INTERACT-P Survey: Demographic Data and Trial Monitoring in the NHS

Thank you for taking the time to complete this survey which is part of a service evaluation.

The aim of this survey is to gain a comprehensive understanding of how NHS Trusts and Health Boards across the UK routinely collect and record patient demographic data and clinical trial participation information. Your responses will help us better understand current practices around tracking trial participation, including how patients are approached, invited, recruited, and how this information is recorded in electronic patient records (EPR) systems or other platforms.

We are also interested in learning about any routine audits your organisation conducts to monitor parity of trial access and participation across different demographic groups.

Who should complete this survey?
This survey is intended for completion by someone within your R&D department who has expertise in your organisation's EPR systems and clinical trial processes. For some questions, advice may be needed from colleagues in other departments such as IT, data quality, or statistics teams. A pdf copy has been provided via email to allow easy discussion with other departments.

Important:
- Please request information from appropriate local expert(s) to answer the survey as accurately as possible.
- All responses will be anonymised, results will be reported in aggregate only.
- There are 21 questions, split across three pages.
- We are asking for one response from each NHS Trust.
- Data will be stored securely with limited access according to the ICR's privacy policy (https://www.icr.ac.uk/legal/privacy).

If you have any questions about the survey or the project, please contact interact-icrctsu@icr.ac.uk.

NHS trust details

1. Trust name *

Bolton NHS Foundation

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2. How many clinical trials are being run at your trust currently?

Please include clinical trials currently recruiting or in follow-up

Approx. 50 clinical trials

0/32,000 characters

3. Which type of organisation best describes you?

- (X) 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
- (x) No

5. How many full-time equivalent (FTE) staff are employed by your trust?

- ( ) <250
- ( ) 250-999
- ( ) 1000-2999
- (x) 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.

Ethnicity

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

Preferred language

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

Religion or belief

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

Sexual orientation

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

Sex

- [ ] Not recorded
- [x] Specific field in the EPR
- [x] Elsewhere in the EPR

- [x] Written/hard copy patient notes
- [ ] Other hospital system

Gender

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

Marital status

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

Caring responsibilities

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

Employment status

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

Postcode

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

Other socioeconomic indicators such as accommodation type or Area Deprivation Index

- [x] 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:

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

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

9. Is the completeness of this data checked routinely?

- ( ) Yes
- ( ) No
- (x) 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:

N/A

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

None currently

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Clinical trial participation data

We are looking to understand more about the recording of a patient's clinical trial pathway at NHS trusts and whether this data is routinely audited.

Questions about the recording of clinical trial information

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).

Screened for a clinical trial

- ◯ Yes
- ⊗ No
- ◯ Unsure

Eligible for a clinical trial

- ◯ Yes
- ⊗ No
- ◯ Unsure

Approached about a clinical trial

- ◯ Yes
- ⊗ No
- ◯ Unsure

Declined taking part in a clinical trial

- ◯ Yes
- ⊗ No
- ◯ Unsure

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):

The data is held within local spreadsheets for each study that detail which patient has been screened, recruited, approached and recruited.

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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)

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Ineligible

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

Not approached

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

Declines participation

- [x] 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:

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Questions about your internal audit processes

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

- ( ) Yes
- (x) No
- ( ) Unsure

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

- ( ) Yes
- (x) No
- ( ) Unsure

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

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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.

None currently

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