

## **Enhancing staff data collection and analysis to foster inclusivity**

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The Birmingham BRC and CRF strive to provide an inclusive, diverse research environment, community, and culture. To progress our EEDI vision, we need to collect data against a matrix of characteristics and associated barriers, in co-production with those affected. However, the methods and ethics surrounding collection of these data are not straightforward.

In particular, we have identified issues with data collection from staff surveys, noting poor response rates and provision of limited data. We understand that collecting EEDI data is a sensitive topic; it's important to explain the reasons for collecting the data and their purpose. With patient groups (e.g. PPIE groups), we often circulate surveys/collect data alongside workshops, providing opportunities to discuss the tools and support their completion. However, for staff groups we spend less time providing F2F support or developing relationships, preventing collection of high-quality data. The scale at which we want to collect staff EEDI data, and challenges around staff groups being based across several different organisations (common for BRC/CRFs), means developing relationships/providing F2F support may not be achievable. Our project aims to review local experience of EEDI data collection (NIHR REF, R&D in-house staff survey, CRN PRES) and develop novel methods to facilitate this moving forward.

### Acronyms:

BRC – Biomedical Research Centre

CRF – Clinical Research Facility

CRN – Clinical Research Network

EEDI – Equality, Equity, Diversity and Inclusion

F2F – face to face

NIHR – National Institute for Health and Care Research

PPIE – Patient and Public Involvement and Engagement

PRES – Participant in Research Survey

REF – Race Equality Framework

R&D – Research and Development

## **Socioeconomic status and impact on access to early phase cancer clinical trials at the NIHR UCLH Clinical Research Facility (CRF)**

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### **Background**

We investigated whether social deprivation restricts patients’ access to early phase cancer trials within a central London CRF.

### **Methods**

This is a single-centre analysis of cancer patients enrolled in early-phase trials at the UCLH CRF, between 01-Jan-2017 – 31-Dec-2023. We gathered demographic data and calculated socioeconomic deprivation (Indices of Multiple Deprivation (IMD ranking)<sup>1</sup> and compared to local and national averages from the NCRAS database<sup>2</sup> (2006-2015).

### **Results**

We analysed 477 patients over a 7-year period. Patients with no recorded demographics were excluded from analysis (n=99, 17%). Mean age at consent was 60 (17-87). M:F ratio was 1.2:1. Table 2 shows ethnicity data.

There was a significant difference in IMD ranking between enrolled CRF patients compared to the England average, with fewer patients enrolled from more deprived areas (p=0.001, Table 2). This was more prevalent in White patients (p<0.01). No difference seen in Non-White patients (p=0.1366).

The majority of enrolled patients were external referrals (n=265, 57%) with 50% travelling over 20-miles driving distance and 27% >50-miles (range 0.5-513 miles). Externally referred patients were predominantly from the least deprived areas (p<0.01). No difference was seen between internal referrals and England NCRAS data (p=0.7018). Interestingly, London patients were from less deprived areas compared to the London NCRAS data (p<0.01) (Table 3).

### **Conclusion**

Patients enrolled to early phase trials at our unit, were predominantly from affluent socioeconomic backgrounds, compared to regional and national averages. We plan to explore the factors underlying this recruitment bias, and what steps can be taken to improve equality of access.

### **References**

- [1] - <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019>
- [2] - <https://imd-by-postcode.opendatacommunities.org/imd/2019>

**Table 1**

Characteristics	UCLH Clinical Research Facility	NCRAS (England Cancer Rates)	NCRAS (London Cancer Rates)
<b>Patients</b>			
All	477	1262666	144928
<b>Sex</b>			
Male	259 (54%)	598215	68196
Female	218 (47%)	664451	76732
<b>Ethnicity</b>			
White	391 (82%)	1181322 (93.5%)	105746 (73%)
Black	30 (6.3%)	25556 (2%)	15970 (11%)
Asian	28 (5.9%)	36673 (3%)	14935 (10%)
Mixed	4 (0.8%)	5730 (0.5%)	1999 (1%)
Other Ethnic Group	24 (5%)	13385 (1%)	6278 (4%)
<b>Median Age</b>			
All	60		
White	64		
Black	42		
Asian	30		
Mixed Ethnic Groups	46		
Other Ethnic Group	48		

**Table 2**

Social Deprivation Score							
Patient Group	1 (Most Deprived)	2	3	4	5 (Least Deprived)	Total	Chi Square
England (NCRAS)	264983 15%	320800 18%	370951 21%	410793 23%	423839 24%	1791366	N/A
UCLH Clinical Research Facility	37 8%	93 20%	96 21%	117 25%	123 26%	466	<b>0.001</b>
White	22 6%	71 19%	80 21%	98 26%	111 29%	382	<b>&lt;0.01</b>
Non-White	15 18%	22 26%	16 19%	19 23%	12 14%	84	0.1366

\* Statistical significance p=0.01. Bold indicates statistical significance.

**Table 3**

Social Deprivation Score							
Patient Group	1 (Most Deprived)	2	3	4	5 (Least Deprived)	Total	Chi Square
England (NCRAS)	264983 15%	320800 18%	370951 21%	410793 23%	423839 24%	1791366	N/A
External Referrals	13 5%	51 19%	53 20%	72 27%	76 29%	265	<b>&lt;0.01</b>
Internal Referrals	24 12%	42 21%	43 21%	45 22%	47 23%	201	0.7018

\* Statistical significance p=0.01. Bold indicates statistical significance.

## **Harnessing the power of natural language processing to explore inclusive recruitment strategies in the NHS**

Sarindi Aryasinghe, Catalina Carengo, Kerri-Ann Barnett, Rabia Khalid, Koya Greenaway  
Harvey, Louise Clark, Erik Mayer

Diverse NHS staff are essential to delivering high-quality, person-centred services, yet Black and Minority Ethnic (BME) staff are underrepresented in senior roles. To address this, the BRC Imperial Digital Health team and the People and Organisational Development team at Imperial College Healthcare NHS Trust began a programme in 2023 to assess the Trust's inclusive recruitment initiative. This initiative aims for senior leadership within the Trust to reflect the diversity of the Imperial community.

Using data from September 2021 to January 2024 and free-text letters from hiring managers to the Trust's CEO, the team employed advanced analytics and natural language processing to examine hiring trends by candidate and hiring manager profiles. Findings indicate that gender and ethnicity-compliant panels positively influence the scoring of BME female candidates. Moreover, writing the letter to the CEO increased the likelihood of a BME candidate being hired by 1.7 times.

Based on these results, the Trust's senior leadership has committed to enhancing the inclusive recruitment programme by expanding inclusive recruitment training for hiring managers, improving recruitment data quality, and disseminating findings across divisions. This pioneering analysis in the NHS showcases the potential of utilising routinely collected recruitment data to provide real-world evidence on the effectiveness of Equality, Diversity, and Inclusion (EDI) recruitment strategies.

## **Starting with the baseline: Protected Characteristics Project**

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### **Background**

Under-representation in research participation reduces the generalisability of findings, exacerbates poor patient outcomes and increases treatment costs. Little data on protected characteristics, or caring responsibilities or index of deprivation (IMD) is routinely collected from research participants. It is therefore impossible to robustly identify which communities/groups are under-represented in research studies. To address this, we co-developed a questionnaire with members of the public to collect protected characteristics, caring data and IMD. We also involved members of the public in co-creation of KPIs to monitor diversity in research participation.

### **Aim**

- To establish an efficient process to collect participants' protected characteristics data at scale.
- To develop KPIs to be able to measure effectiveness of interventions to widen research participation.

### **Results**

We did an initial pilot to understand processes of distribution and acceptability of the questionnaire we had a return rate of 68.7%. We then approached a bigger sample and had a response rate of 26%. Analysis of the data demonstrated a marked under-representation in research participants from minoritised ethnic backgrounds and those who live in areas of deprivation.

### **Challenges in questionnaire roll-out**

- Inconsistencies between organisations on basic data that is collected for research participants.
- Awareness of consenting process and how some studies fall under CAG
- Organisational differences on how the project is classified (service improvement versus clinical effectiveness)
- Need for flexibility as processes might change along the way.

### **Potential impact of the project**

We anticipate that we will have completed collecting a snapshot of the protected characteristics of research participants in the selected cohorts by the end of March 2025. This baseline data will be used to inform current and planned initiatives to widen and diversify research participation within the Bristol, North Somerset and South Gloucestershire area and beyond, and measure their effectiveness.

## **Baseline data has a bigger story: what we can learn from study and system barriers in data collection**

**Chrissie Adams** EDI Research Associate, NIHR Moorfields CRF and BRC

Our EDI Research Associate established baseline data for all our research participants in clinical trials – which highlighted significant disparities in how we collect and report this data. Instead of showing ‘who’ is missing, it has shown ‘what’ is missing. Identifying significant barriers in data collection.

Categorised into 3 areas to be addressed: Patient Level Barrier, System Level Barrier and Study Level Barrier

System and Study Level Barriers include lack of centralised reporting, lack of continuity in language, lack of mandatory/stipulated element to questions of diversity, multiple data bases, lack of allocated resource/time/importance – and discomfort from researchers in asking.

A new diversity monitoring questionnaire has been developed and tested. It has been deployed on iPads in the CRF Reception for use with participants on their visits.

A self-service option has proved to be successful:

- 100% completed.
- Positive response
- Private space helped with perceived discomfort.
- Accessibility for sight conditions

The results of our study show no patient level barrier- in both our self-service electronic questionnaires we have 100% completion rates (in the CRF Reception) and 96% completion rates on our online research portal (ROAM)

The results provide a strong case for the introduction of diversity monitoring questionnaires as separate forms, provided for every participant, to completed personally on a tablet, within a research setting. This can then be linked to research data bases to upload and store against the studies. Providing a streamlined, time efficient process, that both researchers and research participants are comfortable with.

## **Patient Reported Outcome Data Studies**

Ms Jo O'Neill (Deputy Manager NIHR/WT Birmingham Clinical Research Facility) Mr Byron Batten (NIHR Birmingham BRC EEDI Lead), Dr Victoria Day (Head of NIHR Birmingham BRC), Dr Nicola Anderson (Lead Research Nurse / Study Principal Investigator)

Patient-Reported outcomes (PROs) provide essential safety and tolerability data to inform patient-centred clinical care and regulatory decisions. However, trials using PROs often fail to address cultural and health specificities of populations underserved by research. In research, the result of populations being underserved is that they may not benefit from the valuable PRO data that evidences the risks and benefits of treatment from the patients' own perspective. When this happens systematically, health data poverty occurs, resulting in the absence of vital evidence relating to these groups when informing clinical care, regulatory decisions and health policy.

We plan to deliver a survey and carrying out interviews and group discussions with members of the public accessing the main Hospital entrance foyers, public spaces and outpatient clinics at UHB and another NHS site. Participants can include patients, staff, friends and family of patients.

Potential impact includes:

1. Improve the accessibility and acceptability of PRO data collection in research and routine care settings.
2. Explore the barriers and facilitators for PRO data collection in research and routine care settings from the perspective of those who are underserved by research.
3. Formulate solutions to address barriers to Patient-Reported outcome data collection from groups underserved by research.



## **Facing the challenges of representation in clinical research: developing and piloting a demographic questionnaire at a mental health Clinical Research Facility**

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### **Overview:**

Oxford Health Clinical Research Facility (OHCRF) co-designed a demographics questionnaire with local research teams, and patient and public involvement contributors. NIHR's 2023 guidance was subsequently incorporated. From August 2021, OHCRF research participants have completed the questionnaire anonymously on paper forms during initial study visits. Data is then inputted into a Microsoft form. In August 2023, questionnaire data was compared with local census data (Oxfordshire/Buckinghamshire) and Oxford Health NHS Foundation Trust (OHFT) data (from clinical mental/cognitive health services).

### **Practicalities of delivery on a wider scale:**

This is a practical method of collecting anonymised participant data for local use, and could be implemented in other research clinics, depending on local approvals.

### **Impact:**

The data is being used to understand the OHCRF participant population, and identify under-represented groups.

Following initial data analysis, OHCRF identified actions to promote diversity, e.g. creating "easy read" information and increasing community engagement. Disparities between OHFT (clinical) data and census data informs recruitment avenues and potential collaborative equality, diversity and inclusion work, alongside clinical services.

Questionnaire response rates and missing OHFT data limits the findings. OHCRF implemented measures to increase the response rate. Data will be analysed annually to measure change and increase the robustness of findings.