Invitation architecture and inequitable access to health research: A large cross-sectional study of 43,005 UK adults

Name	ORCID iD	Email
Austen El-Osta 1 *	0000-0002-8772-4938	a.el-osta@imperial.ac.uk
Mohammed Adam 1 §	0000-0002-4228-2494	m.adam@imperial.ac.uk
Sami Altalib 1	0000-0001-7404-8486	sami.altalib22@imperial.ac.uk
Manisha Karki 1	0000-0001-6996-8915	m.karki@imperial.ac.uk
Aos Alaa 1	0000-0001-6130-5092	aos.alaa18@imperial.ac.uk
Haitham Idriss 1	0000-0001-9676-1266	haitham.idriss19@imperial.ac.uk
Adi Behura 1		aditya.behura22@imperial.ac.uk
Laura Mitchell 2		laura.mitchell@ourfuturehealth.org.uk
Ashnee Dhondee 3		ashnee.slade1@nhs.net
Prital Patel 3		prital.patel@nihr.ac.uk
Zara Prem 3		zara.prem@nihr.ac.uk
Mounia Igheldane 4		m.igheldane@googlemail.com
Jamela Khan 5		jamela.khan22@gmail.com
Hager Mohammed 5		hageribrahim2000@yahoo.com
Asmahan Nouman 5		renad204@hotmail.com
Arti Sharma 3		arti.sharma@nihr.ac.uk
Sandra O'Sullivan 3		sandra.o'sullivan@nihr.ac.uk
David Mummery 6		david.mummery@nhs.net
Waseem Jerjes 6	000-0002-6914-7401	waseem.jerjes@nhs.net
Azeem Majeed 6	0000-0002-2357-9858	a.majeed@imperial.ac.uk

1- Self-Care Academic Research Unit (SCARU), School of Public Health, Imperial College London, Wood Lane, London W12 0BZ, UK
2- Our Future Health, 9 Holborn, London EC1N 2LL, UK
3- North London Regional Research Delivery Network, NIHR, Barts Health NHS Trust, Canary Wharf Offices, 20 Churchill Place, London E14 5HJ, UK
4- The Nourish Hub, Unit A, Swanscombe House, 1 St Ann's Road, Shepherd's Bush, London W11 4SS, UK
5- Al Manaar Muslim Cultural Heritage Centre, 244 Acklam Road, London W10 5YG, UK
6- Department of Primary Care & Public Health, School of Public Health, Imperial College London, 90 Wood Lane, London W12 0BZ, UK

***Corresponding author:** Dr Austen El-Osta, Self-Care Academic Research Unit (SCARU), Imperial College London Department of Primary Care & Public Health, School of Public Health, Wood Lane, W12 0BZ, UK; Tel. 0207 594 7604; a.el-osta@imperial.ac.uk

§ Shared first author

Abstract

Background
Under-representation in health and social care research threatens the validity, equity and legitimacy of evidence. Although individual barriers to participation are well described, less is known about how structural exposure to research opportunities, particularly healthcare-mediated invitation, relates to participation. We examined sociodemographic, motivational and exposure-related factors associated with participation, satisfaction and prior refusal among UK adults.

Methods
We conducted a cross-sectional online survey of 43,005 UK adults aged ≥16 years between July 2024 and June 2025 using non-probability digital recruitment. Multivariable logistic regression examined prior participation and refusal, and ordinal logistic regression examined satisfaction among previous participants. Missing covariate data were addressed using multiple imputation by chained equations. Geographic variation was assessed across UK regions.

Results
Overall, 39.4% reported previous participation and 71.9% of previous participants were somewhat or extremely satisfied; only 16.2% recalled healthcare-mediated invitation. Invitation showed the strongest association with participation (aOR 8.63; 95% CI 8.03–9.27). Perceived benefit was associated with greater participation (aOR 1.79; 95% CI 1.54–2.07), greater satisfaction (aOR 1.61; 95% CI 1.30–1.99), and lower odds of refusal (aOR 0.76; 95% CI 0.63–0.91). University education (aOR 1.96) and previous work in health, care or research (aOR 1.67) were also associated with participation. Black respondents had lower odds of participation than White respondents (aOR 0.75; 95% CI 0.61–0.92), while Asian, Mixed and Other ethnic groups reported lower satisfaction and higher odds of refusal. Participation and refusal varied across UK regions.

Conclusions
Healthcare-mediated invitation was more strongly associated with research participation than motivational or sociodemographic characteristics. Differential exposure to structured invitation pathways may contribute to inequalities in research engagement. Strategies to broaden participation should address not only willingness and awareness, but also how opportunities are distributed through healthcare and research systems.

Keywords
Health research participation; research engagement; public involvement; health equity; underrepresentation; survey methods; UK public; structural barriers; inclusive research

Introduction

Underrepresentation in health and social care research threatens the external validity, equity, and legitimacy of evidence. When certain populations are systematically less likely to be recruited, invited, or retained, findings may not generalise to those who bear disproportionate disease burdens. Inequitable participation is present across clinical trials and observational studies, particularly among ethnic minority populations, socioeconomically disadvantaged groups, older adults, and individuals with disabilities (1-3). Underrepresentation may also limit access to innovative therapies and reinforce persistent disparities in health outcomes (4, 5).

In the United Kingdom (UK), improving inclusion in research participation is a strategic priority. The National Institute for Health and Care Research (NIHR) INCLUDE guidance highlights persistent exclusion of underserved groups and calls for structural redesign of recruitment pathways (6). National policy frameworks including the UK Policy Framework for Health and Social Care Research similarly emphasise public involvement and equitable engagement as core components of research governance (7). Implementation remains challenging: a UK survey of 945 research professionals identified community outreach and improved communication as important enablers of inclusion, while time, funding and organisational processes constrained engagement with underserved groups (8). However, most existing studies focus on trial-specific recruitment or demographic correlates and rarely integrate invitation exposure, motivation, participation, and refusal within a unified population-level framework.

Empirical analyses of trial enrolment demonstrate persistently lower participation among racial and ethnic minority groups, even after accounting for eligibility (9). Similar inequities have been documented in cancer clinical trials (10) and cardiovascular research (11, 12). Systematic and narrative reviews consistently identify logistical barriers, mistrust, limited awareness and structural exclusion as key contributors (13-15). While mistrust and attitudinal explanations are frequently invoked, procedural and structural factors may exert disproportionate influence. Clinical trial participation can be conceptualised as a sequential pathway in which structural availability, eligibility, clinician offer and patient decision each determine whether participation is possible (16). Population-level evidence also suggests that invitation itself is socially patterned: in a nationally representative US survey, only 9% of adults reported having been invited to a clinical trial, and 47% of those invited subsequently participated (17).

Structural barriers, including eligibility criteria, recruitment practices, and institutional outreach mechanisms, may shape participation opportunities independently of individual willingness. Behavioural models such as COM-B conceptualise participation as arising from capability, opportunity and motivation (18), while health services utilisation frameworks emphasise predisposing, enabling, and need-related factors (19). Together, these perspectives suggest that research participation can be understood as the interaction of structural exposure to opportunity (e.g., invitation), motivational orientation (e.g., perceived benefit), and enabling resources (e.g., education, prior system familiarity). Accordingly, we conceptualised research participation as a function of

interacting three interacting components (**Equation 1**). In this formulation, exposure (e.g., healthcare-mediated invitation) is necessary but not sufficient; motivational and enabling factors may modulate conversion of opportunity into action.

$$\text{Participation} = f(\text{Exposure, Motivation, Enabling Resources})$$

Despite recognition of structural determinants, much of the literature remains trial-specific or condition-specific. Large-scale, population-based analyses examining awareness, invitation exposure, participation, satisfaction, and refusal within a single framework remain scarce. Moreover, geographic variation in research engagement has received comparatively limited attention, although recruitment-site selection can itself influence whether underserved populations are positioned to receive opportunities to participate (20).

Although public engagement with research is needed for democratic accountability and evidence legitimacy (21), robust national epidemiological mapping of who is asked, who participates, who declines and who reports satisfactory experiences remains limited. The Research Heroes Study was designed to address this gap. Using a large-scale cross-sectional survey of more than 43,000 UK-resident adults, this study provides a comprehensive assessment of awareness, invitation exposure and research engagement. Importantly, it moves beyond descriptive prevalence estimates to model independent predictors of (i) active participation, (ii) satisfaction with participation, and (iii) prior refusal. By integrating demographic, perceptual and procedural variables, particularly healthcare-mediated invitation, this analysis provides population-level insight into the architecture of research inclusion. We hypothesised that healthcare-mediated invitation would show a stronger association with participation than demographic or attitudinal factors.

The primary aim of this study was to examine the sociodemographic, motivational and exposure-related factors associated with participation in health and social care research among UK adults, with particular emphasis on healthcare-mediated invitation as a structural determinant of research opportunity. Specifically, we sought to identify independent predictors of (i) prior research participation, (ii) satisfaction among those who had participated, and (iii) prior refusal to participate, and to examine geographic variation in participation and refusal across UK regions. We hypothesised that healthcare-mediated invitation would be more strongly associated with research participation than demographic or attitudinal factors.

Methods

Study Design and Recruitment

We conducted a cross-sectional online survey of UK residents aged ≥16 years between 4 July 2024 and 16 June 2025. Reporting follows the STROBE statement for cross-sectional studies (**Supplementary File 1)** and the CHERRIES checklist for internet surveys **(Supplementary File 2).**

The target population comprised community-dwelling adults aged ≥16 years living in the UK. Participants were recruited through non-probability digital sampling, primarily via the NIHR Be Part of Research (BPoR) network, voluntary and community sector organisations (including local charities and national organisations focused on mental health and social wellbeing), institutional mailing lists and targeted social media outreach. No sampling quotas were applied. The study size was determined by the number of consenting eligible respondents recruited during the study period.

Eligibility required UK residence, age ≥16 years, internet access, and electronic consent. Duplicate and non-consenting responses were excluded. Because recruitment relied on digitally engaged networks, findings reflect a large reachable UK population rather than a nationally representative sample.

Survey Development and Measures

The 33-item survey was co-produced with researchers, community champions, VCSOs, and NIHR delivery partners. It was pilot tested (n=38) and refined for clarity and burden. To promote inclusivity, the final instrument was translated into 17 languages (English, Arabic, Bengali, Brazilian Portuguese, French, Gujarati, Hindi, Polish, Portuguese, Punjabi, Romanian, Romanian, Somali, Spanish, Tagalog, Tamil and Urdu) and reviewed by bilingual community representatives. Items covered six domains: (i) research awareness; (ii) perceived value; (iii) invitation and participation experience; (iv) motivations and barriers; (v) engagement preferences; and (vi) sociodemographics (age, gender, ethnicity, region, education, employment, disability, English proficiency, and prior work in health/care/research). Multiple choice, Likert-type and open-ended response options were used. Adaptive logic limited follow-up items to relevant respondents (e.g., satisfaction assessed only among prior participants). The full instrument is provided as **Supplementary File 3.** Participants were permitted to skip questions, so forced-response completeness checks were not used; adaptive display logic limited conditional follow-up items. The survey comprised 33 Qualtrics question elements within one questionnaire block; 31 participant-facing items were explicitly numbered Q1–Q31, with adaptive display logic applied to conditional questions.

Exposure and outcomes

The primary exposure was recall of healthcare-mediated research invitation (“Has a healthcare provider ever informed or invited you to participate?”; Yes/No/Not sure). Invitation was modelled as a three-level categorical variable (Yes, No, Not sure), with No as the reference, because uncertainty about invitation is itself informative about exposure

to research pathways. Perceived benefit of research was modelled in the same way. Because “Not sure” responses fell between “No” and “Yes” on all three outcomes, they were retained as a distinct category rather than reclassified or imputed. Three outcomes (lifetime “ever” measures) were examined: (i) Active participation (Yes/No), (ii) Satisfaction among participants (5-point ordinal scale), and (iii) Prior refusal (Yes/No). All measures were self-reported; temporal ordering between invitation and participation cannot be established.

Data Collection and Study Population

The survey was hosted on Qualtrics XM platform using encrypted links. Login or registration were not required. Anyone with the link could access the survey. Cookies were used to help prevent duplicate survey entries. IP addresses were not retained. Respondents could not go back to view or change their response prior to submission. The questionnaire included a full-postcode item for geographic context; postcode data were not used to identify respondents and are not reported in this analysis. Survey records were pseudonymised and stored on secure Imperial College London servers in compliance with UK GDPR and the Data Protection Act 2018.. No incentives were offered for participation, and no response-time exclusion threshold was applied. Of 43,034 initiators, 43,005 (99.9%) provided consent and were included. Full completion was achieved by 76.3%; partial responses were retained. A total of 29 individuals (0.1%) declined participation and were excluded. Analyses used section-specific denominators reflecting valid responders. Regression models were restricted to non-missing outcomes. Responses were captured directly within Qualtrics. Before consent, the survey introduction identified the collaborating organisations, described the study purpose, stated an estimated completion time of less than 10 minutes, informed respondents that questions could be skipped, and linked to the Participant Information Sheet. Consent was recorded using a Yes/No item; respondents selecting “No” were routed to the end of the survey.

Data Management and Variable Preparation

Data cleaning and recoding were performed using Stata version 18 (College Station, TX: StataCorp LLC). Descriptive analyses characterised the study population and key research engagement metrics. To ensure accurate prevalence estimates, denominators were adjusted based on survey completion progress; specific sections were restricted to valid responders who viewed those questions. For multiple-response items, participants who dropped out before these sections were treated as missing to prevent artificial deflation of response percentages. Before inferential analysis, categorical string variables were converted to standardised numerical formats and ordinal variables such as age group, education and satisfaction were mapped to ordinal scales. High-granularity demographic variables were aggregated for robustness; specifically, ethnicity was collapsed into the five standard UK Census groups (White, Asian, Black, Mixed, Other). “Prefer not to say” responses were treated as missing. “Not sure” responses for healthcare-mediated invitation and perceived benefit were retained as distinct categories in both descriptive and multivariable analyses.

Statistical Analysis

To investigate geographical disparities, a Pearson's chi-square test of independence assessed the association between the UK region and two outcomes: active participation in health and social care research and the history of participation refusal. Northern Ireland was included but interpreted cautiously due to small sample size ($n<50$). No weighting or post-stratification were applied. Following significant omnibus tests ($p<0.05$), post-hoc analyses using adjusted standardised residuals (ASR) were conducted to identify specific regional "hotspots" and "coldspots". An ASR absolute value greater than 1.96 was considered statistically significant. Given the large analytic samples, interpretation emphasised effect estimates and 95% confidence intervals rather than statistical significance alone.

Regression models were restricted to respondents with non-missing outcome data. Imputation addressed missing covariates but not missing outcomes. Three multivariable regression models were constructed to identify independent predictors of research engagement. Model 1 was a binary logistic regression for active participation in health and social care research (Yes/No), Model 2 was an ordinal logistic regression for participants' satisfaction (5-point Likert scale), and Model 3 was a binary logistic regression for refusal history (Ever declined/refused). Predictors across all models included age group, ethnicity, gender identity, prior work history in health or care, healthcare-mediated invitation status, English language proficiency (Beginner, Intermediate, Advanced, Fluent), education level, disability status, and perceived benefit of research. English language proficiency was modelled as a categorical variable in all multivariable regression analyses. Estimates were pooled using Rubin's rules, and results are reported as adjusted odds ratios (aOR) with 95% Confidence Intervals (CI). Statistical significance was defined as $p<0.05$. For **Figure 2**, average marginal predicted probabilities of participation were estimated by invitation status within ethnic groups from the main-effects Model 1, with other covariates averaged over their observed values; no invitation-by-ethnicity interaction term was fitted.

Model specification was guided by a conceptual framework in which participation was hypothesised to reflect the joint contribution of structural exposure (healthcare-mediated invitation), motivational orientation (perceived benefit), and enabling resources (education, language proficiency and sector familiarity). Covariates were therefore included a priori based on theoretical relevance rather than data-driven selection.

Missing Data Analysis and Imputation Strategy

Missing data patterns were evaluated for the analytical samples of all three regression models. Little's global test for Missing Completely at Random (MCAR) was statistically significant for all models ($p<0.001$), indicating that data were not missing completely at random. Missingness was associated with observed variables, making a Missing at Random (MAR) assumption more plausible, although MAR cannot be formally tested. For example, active participants (Model 1) had 32-36% lower odds of missing values compared to non-participants and satisfied participants (Model 2) were less likely to have missing data than those who were dissatisfied or neutral. Because missingness in invitation and perceived benefit variables was <0.3%, complete-case estimation for these predictors was unlikely to materially influence estimates.

To reduce potential bias from missing covariate data and improve statistical efficiency, Multiple Imputation by Chained Equations (MICE) was employed. Imputation models were specified based on variable type: ordinal logistic regression for age, English skills and education; multinomial logistic regression for ethnicity; augmented multinomial logistic regression for gender; and binary logistic regression for work history and disability status. While imputation was also attempted for invitation status and perceived benefits, technical limitations (likely due to perfect prediction) resulted in residual missingness for these specific variables in the imputed datasets. Consequently, these two predictors were handled using available complete observations. Full percentages of missingness for each predictor in all three models are reported in **Supplementary Table 1**.

The number of imputations (M) was chosen to be sufficiently large to keep Monte Carlo error for regression coefficients and standard errors negligible; this required at least 20 imputations for Models 1 (Active Participation) and 3 (Refusal History), forty imputations were required for Model 2 (Participant Satisfaction), given its smaller analytic sample and similar levels of missingness. The analytic samples were defined by availability of outcome data rather than by covariate deletion: N=35,665 for Model 1 and N=35,241 for Model 3, corresponding to respondents who reached and answered the participation and refusal items respectively (the reduction from 43,005 reflects survey drop-out before these items). A further 0.1–0.2% of these respondents were excluded because of residual missingness in invitation status and perceived benefit. For Model 2, the sample (N=13,820) comprises participants who provided a valid satisfaction rating.

Patient and public involvement

Patient and public involvement was integrated across the design, development and dissemination of the Research Heroes Study. The survey was co-produced with community representatives, voluntary and community sector organisations, and research delivery stakeholders to ensure relevance and cultural responsiveness. Community champions from the Nourish Hub (London Borough of Hammersmith and Fulham) and Al Manaar Mosque (London), together with delivery managers from the NIHR Research Delivery Network North London, contributed to iterative refinement of content, wording and accessibility, shaping items on research awareness, invitation, perceived benefit, barriers and communication preferences, with attention to underserved groups.

The draft survey was pilot tested with 38 members of the public, leading to minor revisions to terminology, flow and length. The final instrument was translated into 17 languages and reviewed by community champions for linguistic and cultural appropriateness. Public partners also advised on recruitment and dissemination through community, voluntary sector and digital channels to extend reach beyond research-active populations. Participants were not involved in statistical analysis. Findings will be shared in accessible formats via community and digital platforms.

Ethics

Ethical approval was granted by the Imperial College Research Ethics Committee (ICREC; reference 6658968), and the study was registered through the NIHR Central Portfolio Management System (CPMS; ID 60665). The study was conducted in

accordance with the Declaration of Helsinki and relevant national and institutional data-governance frameworks. The questionnaire included a full-postcode item for geographic context; postcode data were not used to identify respondents and are not reported in this analysis. Survey records were pseudonymised and no IP addresses were retained. Participants provided electronic tick-box consent to participate in the study. No identifiable individual information is reported in the analysed dataset or manuscript.

Results

Participant Characteristics

A total of 43,005 individuals participated in the survey. The vast majority completed the survey in English (99.5%), with only a small fraction using other languages such as Polish (0.2%) or Spanish (0.1%); **Table 1**. Full participant characteristics are summarised in **Supplementary Table 2**.

Survey completion varied: 32,833 participants (76.3%) completed the questionnaire in full, while 10,172 (23.7%) provided partial responses. Among the 10,172 partial responders, most stopped early, with progressively smaller numbers dropping out at later stages of the questionnaire. Item-level missingness therefore varied by section and primarily reflected survey dropout rather than systematic exclusion. Reasons for early survey termination were not collected.

Sociodemographic Profile

Sociodemographic data were available for approximately 76% of respondents, with missingness ranging from 23.4% (age, gender, ethnicity) to 24.7% (region), largely due to survey drop-out. Among those reporting age (n=32,952), the sample was skewed older: 33.1% were aged ≥65 years and 25.1% were 55–64, while 17–24-year-olds comprised 3.5%. Participants were predominantly female (61.8%) and White British (80.8%). Over half (53.2%) held a university degree or higher. The most common employment status was retired (28.0%), followed by full-time (24.5%) and part-time employment (10.2%). A total of 27.6% reported a disability, and 33.4% had current or prior experience in health, care or research.

Respondents were distributed across all UK regions, predominantly in England, with the highest representation from Kent, Surrey and Sussex (9.9%), East of England (9.4%), and Yorkshire and Humber (9.3%). Within London (n=3,760), Barnet and Bromley (each 4.8%) were most represented. Smaller numbers were from Scotland (n=125), Wales (n=163) and Northern Ireland (n=30).

Table 1: Participant characteristics (N=43,005).

Variable	Frequency (Percentage)
Survey language	
English	42,783 (99.5%)
Other languages (12 languages)	222 (0.5%)
Age group (N-Miss 10,053)	
16–24	1,146 (3.5%)

25–34	3,296 (10.0%)
35–44	4,017 (12.2%)
45–54	5,311 (16.1%)
55–64	8,268 (25.1%)
65 and over	10,914 (33.1%)
Gender identity (N-Miss 10,053)	
Male	12,047 (36.6%)
Female	20,369 (61.8%)
Other (including non-binary)	397 (1.2%)
Prefer not to say	139 (0.4%)
Ethnicity (2021 Census groups) (N-Miss 10,053)	
White	29,486 (89.5%)
Asian/Asian British	1,245 (3.8%)
Black/African/Caribbean/Black British	503 (1.5%)
Mixed/Multiple ethnic groups	1,023 (3.1%)
Other ethnic group	486 (1.5%)
Prefer not to say	209 (0.6%)
English language skills (N-Miss 10,255)	
Beginner	125 (0.4%)
Intermediate	658 (2.0%)
Advanced	1,224 (3.7%)
Fluent	30,743 (93.9%)
Highest level of education (N-Miss 10,400)	
Basic level	612 (1.9%)
Secondary/high school	4,783 (14.7%)
A Levels or equivalent	6,233 (19.1%)
Apprenticeship/training	3,143 (9.6%)
University degree or above	17,338 (53.2%)
Prefer not to say	496 (1.5%)
Disability (Equality Act 2010 definition) (N-Miss 10,245)	
Yes	9,048 (27.6%)
No	23,029 (70.3%)
Prefer not to say	683 (2.1%)
Currently or previously worked in health, care or research (N-Miss 10,259)	
Yes	10,939 (33.4%)
No	21,807 (66.6%)
UK nation/other location (derived from regional item (N-Miss 10,604)	
England	30,809 (95.1%)
Scotland	125 (0.4%)
Wales	163 (0.5%)
Northern Ireland	30 (0.1%)
Other/not stated	1,274 (3.9%)
N-Miss denotes respondents who did not reach or did not answer the item; percentages are calculated among valid responders. Ethnic groups are collapsed to the five 2021 Census categories used in the regression models.	

Awareness, Perceptions and Community Priorities of Research

Awareness varied by research type. Clinical/healthcare research (67.1%) and market research (61.2%) were most recognised, followed by public health research (56.5%), while charitable research was least recognised (29.6%); **Supplementary Table 3**. Although general awareness was high, knowledge of local research activity was limited: only 6.3% were aware of health and social care research in their area, whereas 71.6% were not. Perceived value remained high, with 79.2% agreeing that such research benefits them, their families and local communities.

When prioritising topics for their area, respondents most frequently selected health conditions/disease (55.3%) and mental health and wellbeing (54.1%), followed by access to healthcare services (27.3%) and social isolation (25.2%). Preferences favoured digital participation, with 90.1% selecting online surveys versus 48.3% for face-to-face interviews; 74.4% expressed interest in clinical trials. Email was the preferred channel for receiving study information and findings (95.3%), substantially exceeding online portals (30.6%) and postal mail (26.0%); **Supplementary Table 3**.

Participation Experience and Motivations

Approximately 39.4% of respondents reported having actively participated in health and social care research studies. Among those who had participated (n=14,062), satisfaction levels were generally high, with 71.9% reporting being either "somewhat" or "extremely" satisfied. Furthermore, 85.0% of participants felt they were given sufficient information before agreeing to join a study. Motivation was primarily altruistic; "desire to help others" was the leading driver (80.1%), followed by personal interest in the research topic (59.8%). Financial compensation (9.7%) and external encouragement (7.5%) played significantly smaller roles in motivating participation (**Table 2** and **Supplementary Table 3**).

Barriers, Facilitators and Research Communication

While most respondents had not declined a study, overall, 11.0% reported having previously declined participation. Among those who refused, the most common reasons were lack of time (43.6%) and lack of interest in the topic (25.0%). Across the full sample, frequently cited barriers included time constraints (41.5%), lack of relevant studies for their condition (36.0%), and lack of awareness (34.9%). Key facilitators included access to new treatments and better care (58.7%), improved understanding of personal health (53.3%), and financial compensation (48.0%); **Table 2** and **Supplementary Table 3**.

Perceptions of research communication were largely unfavourable: 46.1% rated dissemination by health and social care organisations as “poor” or “very poor,” 46.2% were neutral, and 7.7% rated it “well” or “very well.” Completing the survey increased awareness of research opportunities for 58.1% of respondents, and 98.3% reported that the questionnaire was easy to understand and complete (**Table 2**).

Multiple-response items, including types of research recognised, community research priorities, motivations, reasons for refusal, facilitators, participation preferences and preferred information channels, are provided in full in **Supplementary Table 3**.

Table 2: Awareness, attitudes and experiences regarding health and social care research (N=43,005).

Variable	Frequency (Percentage)
Aware of health & social care research happening in your area (N-Miss 7,324)	
Yes	2,243 (6.3%)
To some extent	6,140 (17.2%)
No	25,535 (71.6%)
Not sure	1,763 (4.9%)
Research could be beneficial to you, your family & local community (N-Miss 7,353)	
Yes	28,245 (79.2%)
No	1,149 (3.2%)
Not sure	6,258 (17.6%)
Ever informed about or invited to research by a healthcare provider (N-Miss 7,356)	
Yes	5,774 (16.2%)
No	27,527 (77.2%)
Not sure	2,348 (6.6%)
Ever actively participated in health & social care research (N-Miss 7,340)	
Yes	14,062 (39.4%)
No	21,603 (60.6%)
Satisfaction with experience (participants only, N=14,062; N-Miss 242)	
Extremely dissatisfied	711 (5.1%)
Somewhat dissatisfied	537 (3.9%)
Neither satisfied nor dissatisfied	2,644 (19.1%)
Somewhat satisfied	4,540 (32.9%)
Extremely satisfied	5,388 (39.0%)
Given sufficient information before agreeing to participate (participants only, N=14,062; N-Miss 228)	
Yes	11,753 (85.0%)
To some extent	1,751 (12.7%)
No	147 (1.1%)
Not sure	183 (1.3%)
Ever declined or refused to participate in a research study (N-Miss 7,764)	
Yes	3,893 (11.0%)
No	31,348 (89.0%)
How well organisations communicate research findings (N-Miss 10,229)	
Very poorly	4,964 (15.1%)
Poorly	10,155 (31.0%)
Neutral	15,141 (46.2%)
Well	2,106 (6.4%)
Very well	410 (1.3%)
Survey increased awareness of research opportunities (N-Miss 10,176)	
Yes	19,062 (58.1%)
No	13,767 (41.9%)
Survey easy to understand & complete (N-Miss 10,195)	
Yes	32,249 (98.3%)
No	561 (1.7%)

Predictors of Active Participation in Health and Social Care Research

A binary logistic regression analysis was conducted using 20 imputed datasets (N=35,665) to identify sociodemographic and research-related predictors of active participation (**Figure 1** and **Supplementary Table 4**).

Model fit indicated a significant association between predictors and participation ($F(24, 98541.7) = 198.47$, $p<0.001$). The strongest predictor was healthcare-mediated invitation: individuals informed or invited by a healthcare provider had over eightfold higher odds of participation (aOR 8.63, 95% CI 8.03–9.27, $p<0.001$). Those unsure of invitation status also had increased odds (aOR 1.76, $p<0.001$). Perceived benefit was independently associated with participation; respondents who believed research benefits their community had higher odds of participation (aOR 1.79, 95% CI 1.54–2.07, $p<0.001$).

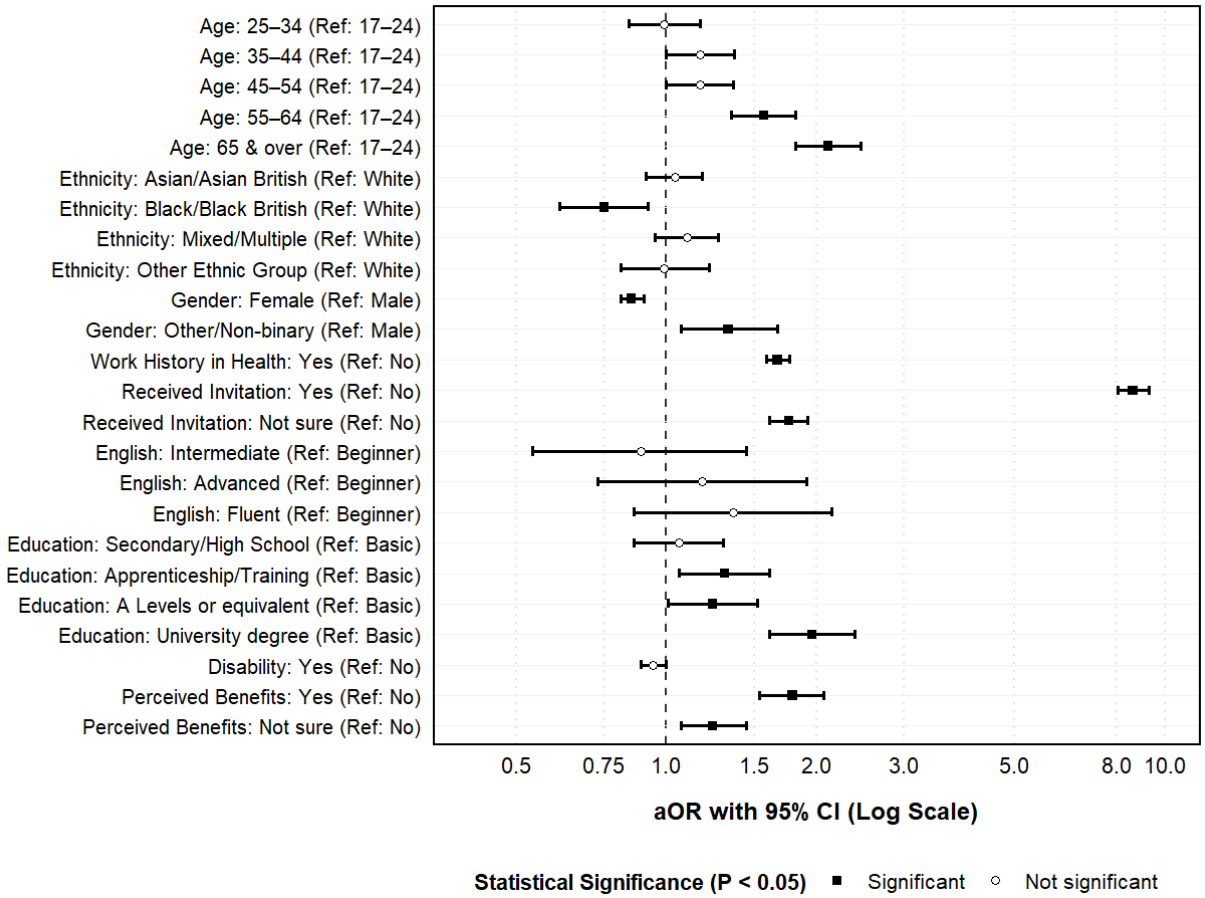


Figure 1: Forest plot of adjusted odds ratios (aORs) with 95% confidence intervals for sociodemographic and research-related predictors of participation in health and social care research. The dashed vertical line at aOR=1.0 indicates no effect; intervals not crossing this line denote statistical significance.

Participation increased with age. Compared with 17–24-year-olds, those aged 55–64 (aOR 1.57, $p<0.001$) and ≥65 years (aOR 2.11, $p<0.001$) were more likely to participate. Female participants had lower odds than males (aOR 0.85, 95% CI 0.81–0.90, $p<0.001$), whereas those identifying as Other/Non-binary had higher odds (aOR 1.33, $p=0.012$).

Black/Black British respondents had lower odds compared with White respondents (aOR 0.75, 95% CI 0.61–0.92, p=0.005); no other ethnic group differences were statistically significant.

Higher education was positively associated with participation: apprenticeship (aOR 1.31, p=0.011), A-levels (aOR 1.24, p=0.039), and university degree (aOR 1.96, p<0.001) versus basic qualifications. Prior work in health, care or research was associated with 67% higher odds (aOR 1.67, p<0.001). English language proficiency was not significant. Disability was marginally associated with lower participation (aOR 0.94, 95% CI 0.89–1.00, p=0.050). **Figure 2**: presents marginal predicted probabilities by invitation status within ethnic groups from the main-effects model; these estimates are descriptive and do not constitute a test of invitation-by-ethnicity interaction.

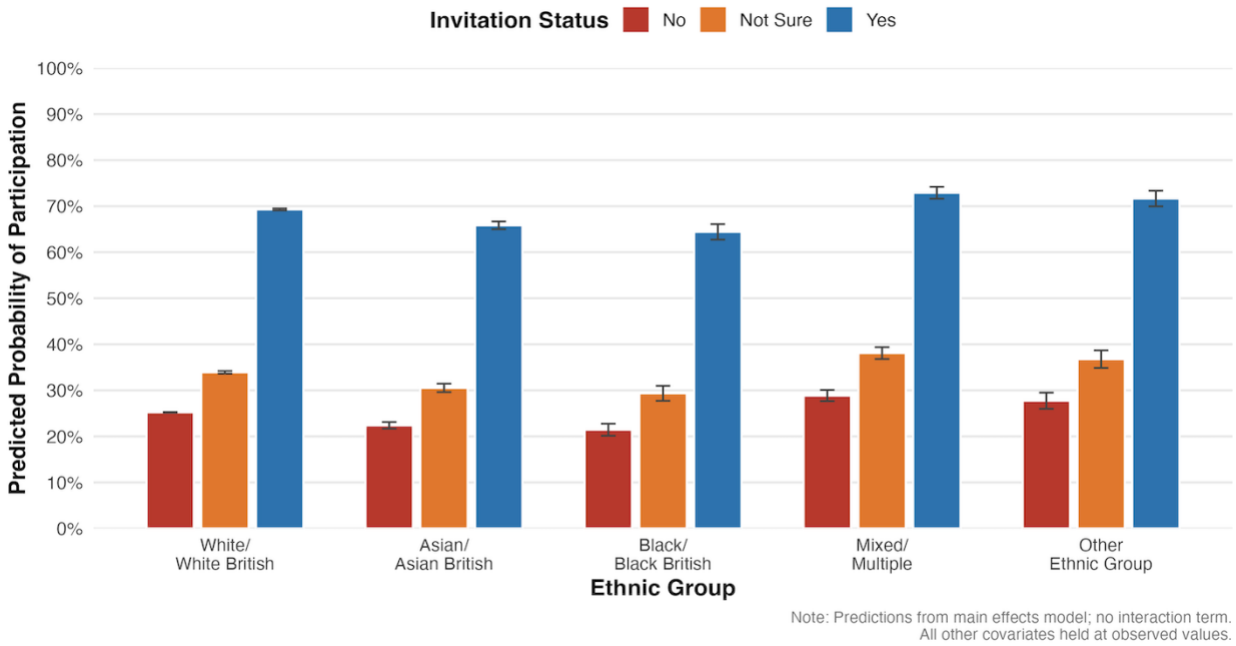


Figure 2: Marginal predicted probabilities of active participation by invitation status within ethnic groups. Estimates are pooled from 20 multiply imputed datasets (N=35,665) using Rubin's rules, with other covariates averaged over their observed values. Error bars show 95% confidence intervals. Predictions are from a main-effects model; no invitation-by-ethnicity interaction term was fitted.

Predictors of Participants' Satisfaction

An ordinal logistic regression using 40 imputed datasets (N=13,820) examined predictors of satisfaction (**Figure 3** and **Supplementary Table 5**). The model was statistically significant (F(24, 311441.5)=11.04, p<0.001). Perceived benefit was the strongest positive predictor: participants who believed research benefits their community had 61% higher odds of greater satisfaction (aOR 1.61, 95% CI 1.30–1.99, p<0.001). Healthcare-mediated invitation was also associated with higher satisfaction (aOR 1.22, 95% CI 1.14–

1.31, p<0.001), whereas uncertainty about invitation was associated with lower satisfaction (aOR 0.86, p=0.018).

Gender was significant, with females reporting higher satisfaction than males (aOR 1.12, 95% CI 1.05–1.20, p=0.001). Compared with White respondents, Asian (aOR 0.73, p<0.001), Mixed (aOR 0.80, p=0.015), and Other ethnic groups (aOR 0.64, p<0.001) reported lower satisfaction. Disability was also negatively associated (aOR 0.77, 95% CI 0.71–0.83, p<0.001). University graduates had higher satisfaction than those with basic education (aOR 1.36, p=0.041). Age, prior work in health/care/research, and English language proficiency were not significant predictors.

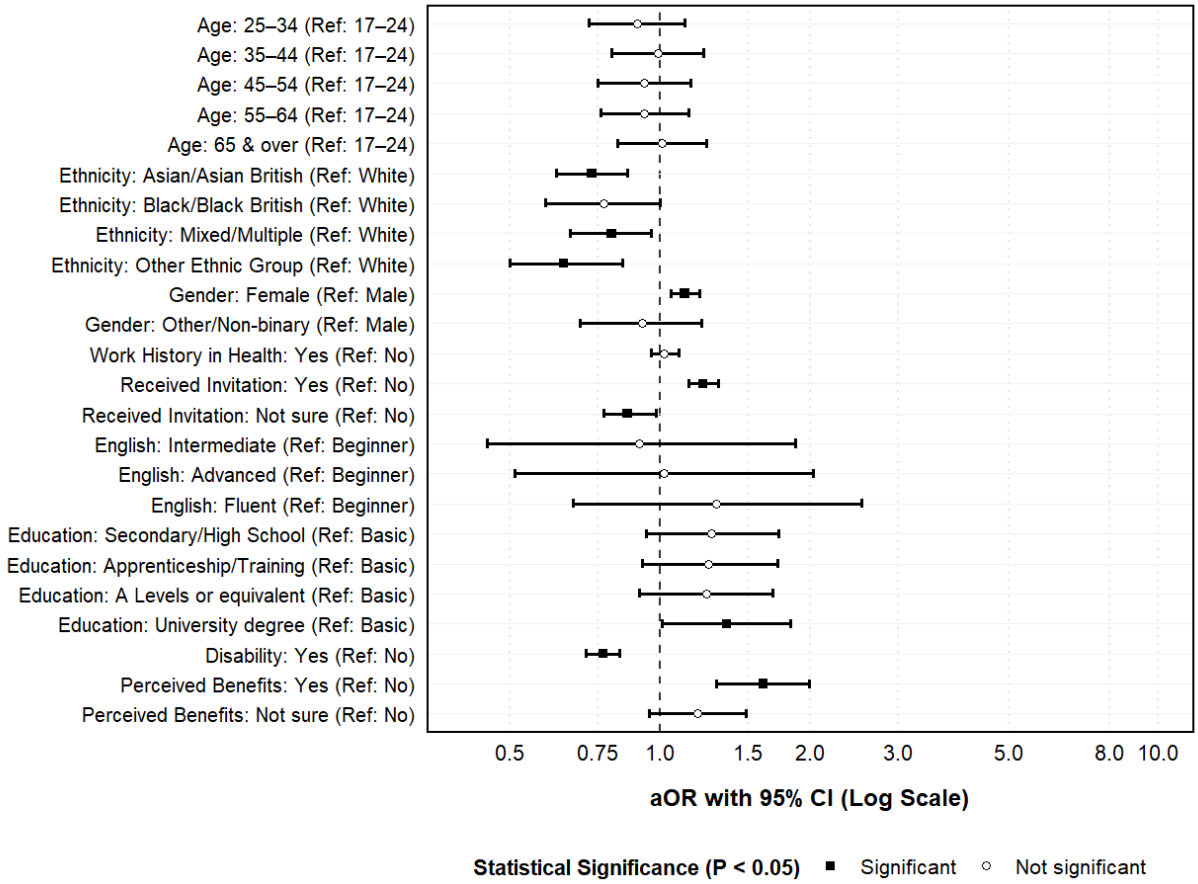


Figure 3: Forest plot of adjusted odds ratios (aORs) with 95% confidence intervals for sociodemographic and research-related predictors of satisfaction with participation in health and social care research. The dashed vertical line at aOR=1.0 denotes no effect; intervals not crossing this line indicate statistical significance.

Predictors of Prior Research Participation Refusal

A binary logistic regression analysis was conducted using 20 imputed datasets (N = 35,241) to identify factors associated with having previously declined participation in research (**Figure 4** and **Supplementary Table 6**). The model was statistically significant (F(24, 94993.0)=46.38, p<0.001). Healthcare-mediated invitation was strongly associated with refusal: those previously invited had nearly threefold higher odds of having declined

participation (aOR 2.82, 95% CI 2.61–3.05, p<0.001), and those unsure of invitation also had increased odds (aOR 1.79, 95% CI 1.58–2.03, p<0.001). Perceived benefit was protective, with lower odds of refusal among those who believed research benefits their community (aOR 0.76, 95% CI 0.63–0.91, p=0.004).

Compared with 17–24-year-olds, participants aged 25–34 (aOR 0.79, p=0.032), 35–44 (aOR 0.73, p=0.003), and 45–54 (aOR 0.69, p<0.001) were less likely to report refusal. Female gender was not significant, whereas those identifying as Other/Non-binary had higher odds (aOR 1.60, p=0.001). Ethnicity was associated with refusal: Asian (aOR 1.23, p=0.019), Mixed (aOR 1.24, p=0.032), and Other ethnic groups (aOR 1.63, p<0.001) had higher odds compared with White respondents. University graduates had higher odds than those with basic education (aOR 1.66, p=0.001), and prior work in health/care/research was also associated with refusal (aOR 1.39, p<0.001). Disability status and English language proficiency were not significant.

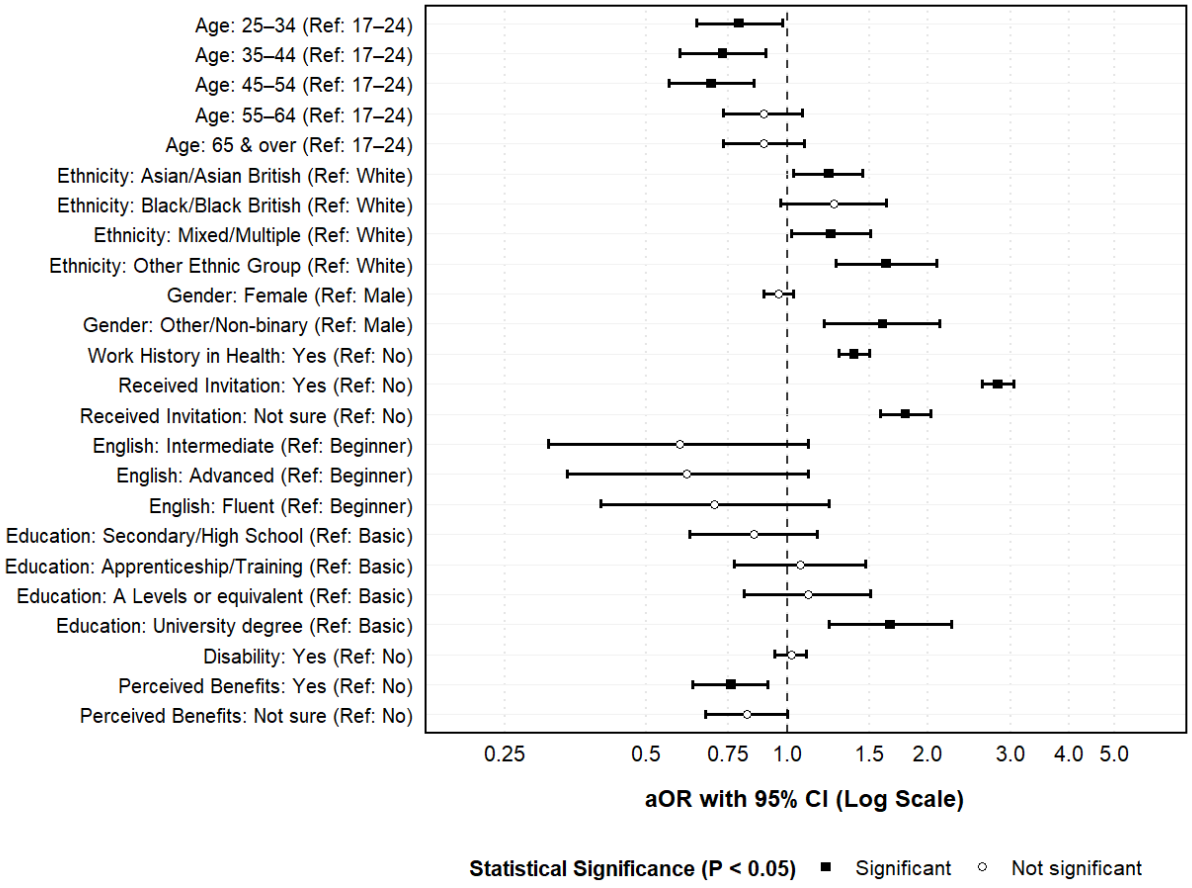


Figure 4: Forest plot illustrating the adjusted odds ratios (aOR) and 95% confidence intervals (95% CI) for sociodemographic and research-related predictors of prior research participation refusal. The dashed vertical line at aOR = 1.0 represents the point of no effect; intervals not crossing this line indicate significant associations.

Analysis by geographic region

Association Between UK Region and Active Participation in Health and Social Care Research

A chi-square test of independence was performed to examine the relationship between UK region and active participation in health and social care research (**Figure 5** and **Supplementary Table 7**). The association between these variables was statistically significant, χ^2 (18, N=32,363)=74.48, p<0.001.

Overall, 40.2% of respondents (n=13,015) reported active participation and 59.8% (n=19,348) reported none. This differs marginally from the 39.4% reported for the full sample because regional analyses were restricted to complete cases with valid data for both region and participation. Participation varied across UK regions, ranging from 37.2% in the West Midlands to 46.3% in Wales, with Northern Ireland excluded from interpretation because of its small sample (n=30).

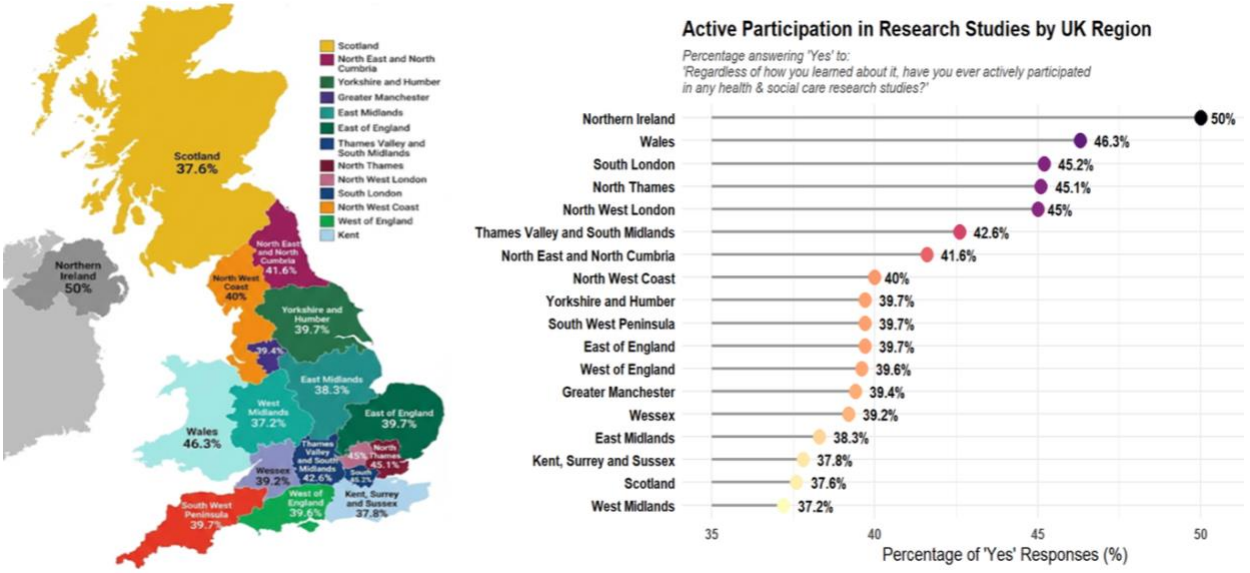


Figure 5: Regional variation in active research participation. (Left) Choropleth map of participation rates by UK region. (Right) Ordered lollipop chart of participation rates by region. Northern Ireland (n=30) is shown for completeness but is not interpreted because of its small sample.

Post-hoc adjusted standardised residuals identified nominal regional deviations from independence. South London (ASR=3.95) and North Thames (ASR=3.86) had higher participation than expected, while the West Midlands (ASR=-3.30) had lower participation; all three remained statistically significant after Bonferroni correction for 19 regional comparisons (|ASR|>3.01). Kent, Surrey and Sussex (ASR=-2.94), North West London (ASR=2.89), Thames Valley and South Midlands (ASR=2.09), and the East Midlands (ASR=-2.08) met nominal thresholds but did not survive the Bonferroni correction (**Table 3**).

Table 3: Post-hoc residual analysis of active research participation by UK region

UK region	Observed (Yes)	Expected (Yes)	Adj. Residual	p-value	Nominal interpretation
South London	650	578.3	3.95	< 0.001	More participation
North Thames	657	586.3	3.86	< 0.001	More participation
West Midlands	1,008	1,088.6	-3.30	< 0.001	Less participation
Kent, Surrey and Sussex	1,210	1,287.3	-2.94	< 0.01	Less participation
North West London	386	345.1	2.89	< 0.01	More participation
Thames Valley and South Midlands	745	703.4	2.09	< 0.05	More participation
East Midlands	1,011	1,061.3	-2.08	< 0.05	Less participation
Other	542	510.3	1.85	> 0.05	Not Significant
Wales	75	65.1	1.58	> 0.05	Not Significant
North East and North Cumbria	874	845.3	1.32	> 0.05	Not Significant
Northern Ireland	15	12.1	1.09	> 0.05	Not Significant
Wessex	733	752.4	-0.94	> 0.05	Not Significant
East of England	1,210	1,226.6	-0.64	> 0.05	Not Significant
West of England	858	871.5	-0.61	> 0.05	Not Significant
Greater Manchester	469	479.0	-0.60	> 0.05	Not Significant
Scotland	47	50.3	-0.60	> 0.05	Not Significant
Yorkshire and Humber	1,197	1,212.1	-0.59	> 0.05	Not Significant
South West Peninsula	600	607.7	-0.41	> 0.05	Not Significant
North West Coast	728	732.3	-0.21	> 0.05	Not Significant

***Note**:* Residuals and counts refer to the 'Yes' (active participation) category. Nominal two-sided p-values are shown. For 19 simultaneous regional comparisons, the Bonferroni-corrected two-sided threshold was |ASR|>3.01 (α=0.05/19). Only South London, North Thames and West Midlands met this corrected threshold. Approximate nominal thresholds are |ASR|>1.96 (p<0.05), >2.58 (p<0.01), and >3.29 (p<0.001).

Association Between UK Region and History of Refusing Research Participation

A chi-square test of independence was performed to examine the relationship between the UK region and prior refusal to participate in research. The association between these variables was statistically significant, $\chi^2(18, N=32,216) = 178.15$, $p<0.001$. Overall, 11.2% of respondents (n=3,610) reported declining or refusing to participate in a research study, while 88.8% (n=28,606) reported never declining. This differs slightly from the 11.0% reported for the full sample because regional analyses were restricted to respondents with complete data on both region and refusal. Refusal rates varied significantly across regions, ranging from 8.9% in Kent, Surrey and Sussex to 17.8% in North West London (**Figure 6** and **Supplementary Table 8**).

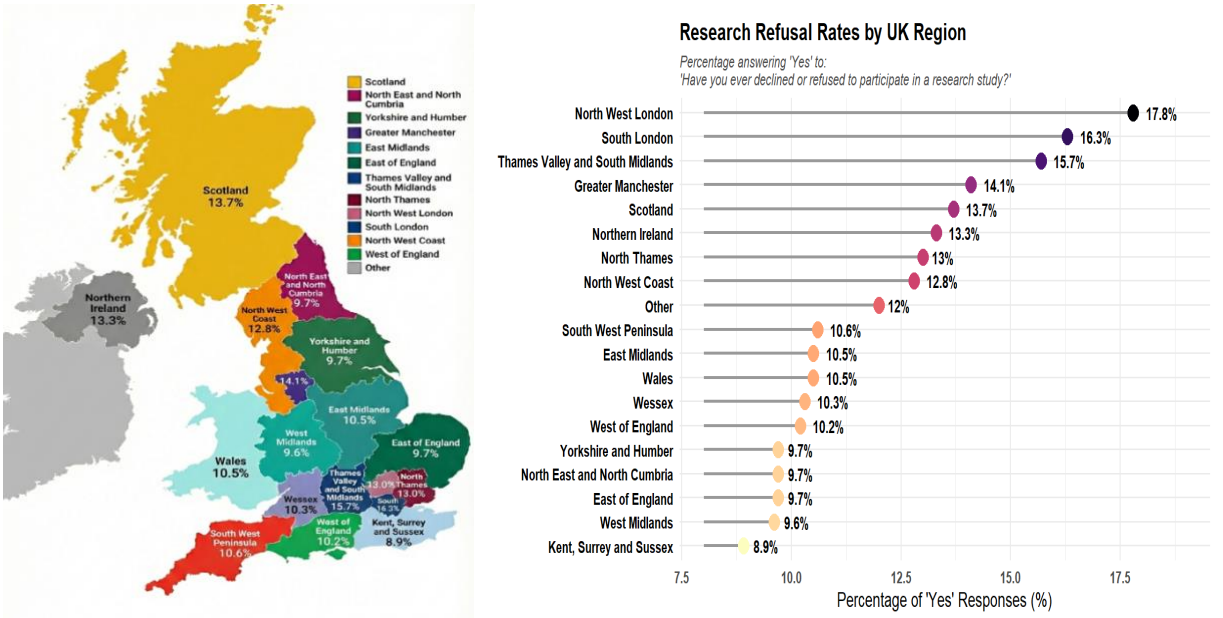


Figure 6: Regional variation in prior refusal to participate in research. (Left) Choropleth map of refusal rates by UK region. (Right) Ordered lollipop chart of refusal rates by region.

Post-hoc adjusted standardised residuals identified nominal regional deviations from independence. Higher refusal than expected was observed in South London (ASR=6.23), North West London (ASR=6.17), Thames Valley and South Midlands (ASR=6.08), and Greater Manchester (ASR=3.19), while Kent, Surrey and Sussex had lower refusal (ASR=-4.39); all five remained statistically significant after Bonferroni correction for 19 regional comparisons (|ASR|>3.01). Other nominal deviations did not survive the corrected threshold **Table 4**.

Table 4: Post-hoc residual analysis of prior research refusal by UK region

UK region	Observed (Yes)	Expected (Yes)	Adj. Residual	p-value	Nominal Interpretation
South London	233	160.4	6.23	< 0.001	Higher Refusal
North West London	152	95.8	6.17	< 0.001	Higher Refusal
Thames Valley and South Midlands	273	195.2	6.08	< 0.001	Higher Refusal
Kent, Surrey and Sussex	283	357.1	-4.39	< 0.001	Lower Refusal
Greater Manchester	167	133.0	3.19	< 0.01	Higher Refusal
Yorkshire and Humber	290	336.4	-2.82	< 0.01	Lower Refusal
West Midlands	259	302.1	-2.75	< 0.01	Lower Refusal
East of England	295	340.0	-2.72	< 0.01	Lower Refusal
North East and North Cumbria	203	235.0	-2.29	< 0.05	Lower Refusal
North Thames	188	162.5	2.17	< 0.05	Higher Refusal
North West Coast	231	203.1	2.14	< 0.05	Higher Refusal
West of England	221	241.9	-1.48	> 0.05	Not Significant
East Midlands	275	294.2	-1.24	> 0.05	Not Significant
Wessex	192	208.3	-1.24	> 0.05	Not Significant
Other	151	140.9	0.93	> 0.05	Not Significant
Scotland	17	13.9	0.89	> 0.05	Not Significant

South West Peninsula	159	168.9	-0.83	> 0.05	Not Significant
Northern Ireland	4	3.4	0.37	> 0.05	Not Significant
Wales	17	18.2	-0.29	> 0.05	Not Significant
Note Residuals and counts refer to the 'Yes' (ever refused) category. Nominal two-sided p-values are shown. For 19 simultaneous regional comparisons, the Bonferroni-corrected two-sided threshold was |ASR|>3.01 (α=0.05/19). South London, North West London, Thames Valley and South Midlands, Kent, Surrey and Sussex, and Greater Manchester met this corrected threshold. Approximate nominal thresholds are |ASR|>1.96 (p<0.05), >2.58 (p<0.01), and >3.29 (p<0.001).					

Discussion

Principal findings

This large national survey provides a contemporary mapping of public engagement with health and social care research in the UK. Research participation was strongly patterned by reported exposure to invitation rather than by demographic profile alone. Although 39.4% of respondents reported prior participation, only 16.2% recalled ever being informed about or invited to research by a healthcare professional. Healthcare-mediated invitation was the strongest independent correlate of participation (aOR 8.63), substantially exceeding the magnitude of motivational and sociodemographic correlates. Perceived benefit of research was associated with higher participation and satisfaction and with lower refusal, but effect sizes were modest relative to invitation exposure. Satisfaction among participants was generally high; however, Asian, Mixed and Other ethnic groups and individuals with disabilities reported lower satisfaction. Prior refusal (11.0%) was also associated with invitation exposure, consistent with refusal being observable only among people who encounter a participation opportunity. Geographic analyses showed regional heterogeneity in both participation and refusal. Over half of respondents reported that completing the survey increased their awareness of research opportunities, suggesting that survey participation itself may have potential to raise perceived research awareness.

The observed pattern is consistent with differential opportunity structures playing a substantial role alongside individual attitudes. Healthcare-mediated invitation was the dominant correlate of participation and exceeded the magnitude of the measured attitudinal factors, including perceived benefit. Inequities in participation may therefore be reinforced by differences in exposure to invitation pathways, although this study did not directly model determinants of who receives an invitation. Because the design is cross-sectional, temporal ordering between invitation and participation cannot be established.

Interpretation in relation to existing evidence

Whereas participation in research can provide individuals with a meaningful voice in shaping evidence, policy and service design (22), underrepresentation in research has been consistently documented across ethnic minority populations, younger adults, individuals with disabilities and socioeconomically disadvantaged groups. National attitudinal surveys in the UK and United States consistently report high public support for health research alongside lower recall of invitation and uneven engagement across

sociodemographic groups (23). In a representative survey of 5,030 UK adults commissioned by the Health Research Authority, 68% reported that they would participate in health and social care research if asked, while 83% trusted research information from a local healthcare professional (24). Cohort studies such as UK Biobank have documented “healthy volunteer” selection effects, with participants disproportionately older, more affluent and more educated than the general population (25). Similarly, the NIH All of Us Research Program has emphasised infrastructure investment and community partnerships to address representational imbalance (26). However, most prior analyses focus on who is enrolled rather than who is invited, who declines, and who reports satisfactory experience. These studies document representational gradients among those enrolled but do not model invitation exposure or refusal behaviour at population scale. Programme-level engagement initiatives, including evaluations of the Patient-Centred Outcomes Research Institute (PCORI) engagement framework, demonstrate that structured patient involvement improves perceived relevance and legitimacy of research (27). Yet again, such evaluations focus on governance and co-production rather than epidemiological mapping of who is asked, who participates and who declines.

Our findings extend this literature by integrating invitation exposure, participation, satisfaction and refusal within a single population-level framework. While clinician endorsement is influential in trial recruitment, few studies have quantified its magnitude at national scale. The observed association between healthcare-mediated invitation and participation (aOR 8.63) suggests that structured exposure to opportunity is a dominant correlate of engagement.

Importantly, this should not be interpreted as causal proof that invitation determines participation. The cross-sectional design precludes temporal sequencing, and unmeasured confounders, such as health status or frequency of healthcare contact, may contribute to the association. Nonetheless, the magnitude of the association is consistent with behavioural frameworks in which opportunity operates alongside motivation and capability. An apparent paradox merits comment. Although healthcare-mediated invitation showed the strongest association with participation, only 16.2% of respondents recalled such an invitation while 39.4% reported having participated, indicating that substantial participation occurred through other routes, including self-referral, registries, community organisations and digital platforms such as BPoR. Healthcare-mediated invitation therefore appears to be a strongly associated but comparatively narrow route to participation. This interpretation is consistent with evidence from cancer research showing that, once participation was actually offered, 55.0% of patients agreed to enrol, suggesting that low aggregate participation cannot necessarily be equated with low willingness among those given an opportunity to participate (28).

Perceived benefit of research independently predicted participation and satisfaction and reduced refusal. This indicates that motivation remains relevant but operates within procedural constraints. The data therefore support a layered model: participation emerges where structural exposure and motivational orientation intersect.

Policy implications: invitation architecture as infrastructure

The strong association between invitation exposure and participation supports considering research access as a systems-design issue as well as an attitudinal one. The present data do not establish that invitation opportunities are unevenly distributed within healthcare pathways, but they identify healthcare-mediated invitation as a potentially important point for future intervention and evaluation.

First, normalisation of routine invitation, using proactive, transparent invitation could be evaluated as a strategy within NHS care pathways rather than dependent on ad hoc clinician actions. Structured prompts within electronic health records could standardise exposure while preserving voluntary participation. Centralised EHR-based recruitment has demonstrated the feasibility of extending trial reach to populations that are otherwise harder to engage, including rural and socioeconomically disadvantaged participants (29). Second, digital recruitment gateways including the integration of research modules within the NHS App could allow individuals to express interest preferences, receive tailored invitations and access plain-language study summaries. Such platforms may reduce reliance on opportunistic in-clinic recruitment. Third, opt-out contact frameworks with carefully governed contact mechanisms for research invitation that is clearly distinct from participation consent could reduce gatekeeping variability. Ethical transparency, data governance and public oversight would be essential. Fourth, experiential equity interventions are needed as lower satisfaction among ethnic minority groups and individuals with disabilities indicates the need for culturally concordant communication, accessibility accommodations, feedback loops and community-based facilitation. Recent evidence on disability inclusion similarly emphasises accessible recruitment and data-collection procedures, flexible study design, supported consent and meaningful involvement of people with disabilities in trial design (30). Finally, regional capacity building especially in areas with persistently lower participation may require investment in research infrastructure, community partnerships and NHS-academic collaboration to ensure equitable exposure. However, the evidence base for interventions that successfully increase representation remains limited. A UK and Ireland scoping review identified few directly evaluated strategies, although GP-originated invitations and community-engagement approaches showed promising signals in specific underserved populations (31).

Strengths and Limitations

This study is one of the largest contemporary surveys of research engagement conducted in the UK, with over 43,000 respondents. The integration of participation, satisfaction and refusal outcomes within multivariable models provides a comprehensive population-level perspective on research engagement. The use of multiple imputation mitigated bias arising from missing demographic data, and the inclusion of regional analyses offers a systems-level dimension often absent from prior work.

The principal limitation of this study is that the sample was not probability-based and differs from population benchmarks. Adults aged 65 years and over comprised 33.1% of respondents compared with 18.6% in England and Wales at Census 2021 (32), while young adults were underrepresented. The sample was also highly educated, with 53.2% reporting a university degree or higher, and included a substantial proportion (33.4%) with

current or prior work in health, care or research. These characteristics indicate self-selection toward older, more educated and research-connected individuals. Consequently, the reported prevalence of prior participation (39.4%) is likely to exceed that in less research-connected populations.

Second, a considerable proportion of responses were obtained via the NIHR BPOR network, which comprises individuals already engaged with research infrastructures. This introduces a selection effect that may both inflate participation prevalence and attenuate observed structural barriers. Findings should therefore be interpreted as reflective of a large, digitally reachable and research-connected UK adult population rather than a nationally representative sample.

Third, key variables including invitation exposure, participation and refusal were self-reported and subject to recall bias. Invitation status reflects perceived exposure rather than verified recruitment records. The cross-sectional design precludes causal inference, and the strong association between invitation and participation may be partially influenced by unmeasured confounding, such as health status or frequency of healthcare contact.

Finally, despite multilingual availability, 99.5% of responses were completed in English, and individuals without internet access were inherently excluded. Structural barriers affecting digitally marginalised or non-English-dominant populations may therefore be underestimated. Future studies using probability-based sampling frames and linkage to recruitment records would enable more precise estimation of structural determinants of research engagement.

Conclusion

This study provides a large-scale epidemiological mapping of research engagement in the UK and shows that participation in health and social care research is strongly associated with reported exposure to healthcare-mediated invitation. Invitation was the dominant measured correlate of participation, while motivational and sociodemographic factors showed smaller associations. The findings are consistent with structured opportunity being an important component of research engagement, but the cross-sectional design does not establish temporal ordering or demonstrate that invitation pathways are themselves inequitably distributed. Persistent differences by ethnicity, disability and region nevertheless identify priorities for further investigation and inclusive recruitment design. Research systems seeking broader participation should therefore consider not only awareness and willingness, but also how opportunities to participate are generated, communicated and experienced.

Declarations

Ethics approval and consent to participate
Ethical approval for the study was granted by the Imperial College Research Ethics Committee (ICREC; reference 6658968), with study registration through the NIHR Central Portfolio Management System (CPMS; ID 60665). All participants provided electronic informed consent before participating in the study. The study was conducted in accordance with the Declaration of Helsinki and relevant national and institutional ethical and data-governance requirements.

Trial registration
Not applicable. This study was a cross-sectional observational survey and did not involve assignment of participants to a health-related intervention.

Consent for publication
Not applicable. The manuscript does not contain identifiable individual participant information, images or videos requiring consent for publication.

Availability of data and materials
The datasets generated and/or analysed during the current study are not publicly available but may be available from the corresponding author on reasonable request, subject to applicable ethical, institutional and data-governance requirements.

Competing interests
The authors declare that they have no competing interests.

Funding
This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. Austen El-Osta and Azeem Majeed are supported by the National Institute for Health and Care Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Authors' contributions
AEO and SOS contributed to the conception of the study. AEO, SA and SOS contributed to study design. MK, AA and AEO contributed to data acquisition. MA and SA conducted the statistical analyses with support from AEO. All authors contributed to interpretation of the findings. AEO led the planning and preparation of the study with support from the co-authors and is the guarantor. All authors critically reviewed the manuscript, approved the final version and agreed to be accountable for the work.

Acknowledgements

The authors thank all members of the public who participated in the Research Heroes Study and generously shared their experiences and perspectives on health and social care research. We are particularly grateful to the NIHR Be Part of Research (BPoR) service for supporting recruitment and dissemination, and to colleagues within the NIHR Research Delivery Network, including the North London Regional Research Delivery Network, for their support in developing and delivering the study.

Twitter: @austenelosta @ImperialSCARU

Supporting Information

- Supplementary File 1. STROBE checklist for cross-sectional studies.
- Supplementary File 2. CHERRIES checklist for internet surveys.
- Supplementary File 3. Full survey instrument.

- Supplementary Table 1: Percentage missingness for each predictor across the three regression models.
- Supplementary Table 2: Full participant characteristics (N=43,005).
- Supplementary Table 3: Full participant awareness, attitudes and experiences regarding health and social care research (N=43,005).
- Supplementary Table 4: Multivariable logistic regression: factors associated with active participation in health and social care research.
- Supplementary Table 5: Multivariable ordinal logistic regression: factors associated with participant satisfaction.
- Supplementary Table 6: Multivariable logistic regression: factors associated with prior refusal of research participation.
- Supplementary Table 7: Distribution of active participation in health and social care research by UK region.
- Supplementary Table 8: Distribution of prior research refusal by UK region.

References

1. Denny CC, Grady C. Clinical research with economically disadvantaged populations. J Med Ethics. 2007;33(7):382-5.
2. Morales-Garzón S, Parker LA, Hernández-Aguado I, González-Moro Tolosana M, Pastor-Valero M, Chilet-Rosell E. Addressing Health Disparities through Community Participation: A Scoping Review of Co-Creation in Public Health. Healthcare (Basel). 2023;11(7).
3. Jain S, Bey GS, Forrester SN, Rahman-Filipiak A, Thompson Gonzalez N, Petrovsky DV, et al. Aging, Race, and Health Disparities: Recommendations From the Research Centers Collaborative Network. J Gerontol B Psychol Sci Soc Sci. 2024;79(6).

4. Bibbins-Domingo K, Helman A. Improving representation in clinical trials and research. Washington DC: National Academies of Sciences, Engineering, and MedicinePolicy and Global Affairs. 2022.
5. Morsi MH, Elawfi B, SA AL, Nazar A, Mostafa HA, Awwad SA, et al. Unveiling the Disparities in the Field of Precision Medicine: A Perspective. Health Sci Rep. 2025;8(8):e71102.
6. Research NIfH. Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project. Leeds: NIHR. 2020.
7. NHS Health Research Authority. UK Policy Framework for Health and Social Care Research. 2020.
8. Coe D, Bigirumurame T, Burgess M, Rouse J, Wroe C. Enablers and barriers to engaging under-served groups in research: Survey of the United Kingdom research professional's views. NIHR Open Res. 2023;3:37.
9. Alarcón Garavito GA, Gilchrist K, Ciurtin C, Khanna S, Chambers P, McNally N, et al. Enablers and barriers of clinical trial participation in adult patients from minority ethnic groups: a systematic review. Trials. 2025;26(1):65.
10. Guadamuz JS, Wang X, Altomare I, Camelo Castillo W, Sarkar S, Mamtani R, et al. Mediators of racial and ethnic inequities in clinical trial participation among patients with cancer, 2011-2023. JNCI Cancer Spectr. 2024;8(5).
11. Bacour N, Grewal S, Ploem MC, Suurmond J, Klautz RJM, Grewal N. Bridging Barriers: Engaging Ethnic Minorities in Cardiovascular Research. Healthcare (Basel). 2025;13(11).
12. Vilcant V, Ceron C, Verma G, Zeltser R, Makaryus AN. Inclusion of under-represented racial and ethnic groups in cardiovascular clinical trials. Heart, Lung and Circulation. 2022;31(9):1263-8.
13. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014;104(2):e16-31.
14. Wiesepape CN, Queller Soza SE, Faith LA. Behind the Gaps: A Narrative Review of Healthcare Barriers for Individuals with Serious Mental Illness. Healthcare (Basel). 2025;13(19).
15. Matin BK, Williamson HJ, Karyani AK, Rezaei S, Soofi M, Soltani S. Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. BMC Womens Health. 2021;21(1):44.
16. Unger JM, Vaidya R, Hershman DL, Minasian LM, Fleury ME. Systematic Review and Meta-Analysis of the Magnitude of Structural, Clinical, and Physician and Patient Barriers to Cancer Clinical Trial Participation. J Natl Cancer Inst. 2019;111(3):245-55.
17. Williams CP, Senft Everson N, Shelburne N, Norton WE. Demographic and Health Behavior Factors Associated With Clinical Trial Invitation and Participation in the United States. JAMA Netw Open. 2021;4(9):e2127792.
18. Michie S, Van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implementation science. 2011;6(1):1-12.
19. Alkhawaldeh A, M AL, Rayan A, Abdalrahim A, Musa A, Eshah N, et al. Application and Use of Andersen's Behavioral Model as Theoretical Framework: A Systematic Literature Review from 2012-2021. Iran J Public Health. 2023;52(7):1346-54.
20. Booth A, McDaid C, Scrimshire A, Singh HP, Scantlebury A, Hewitt C. Using publicly available UK datasets to identify recruitment sites to maximise inclusion of under-served groups: three case studies. NIHR Open Res. 2024;4:18.
21. Frith L. Democratic Justifications for Patient Public Involvement and Engagement in Health Research: An Exploration of the Theoretical Debates and Practical Challenges. J Med Philos. 2023;48(4):400-12.
22. Kost RG, Andrews J, Chatterjee R, Cheng AC, Connally L, Dozier A, et al. What research participants say about their research experiences in Empowering the Participant Voice: Outcomes and actionable data. J Clin Transl Sci. 2025;9(1):e43.

23. Research!America. Public Opinion Survey 2026 [Available from: https://www.researchamerica.org/category/public-opinion-survey/.
24. NHS Health Research Authority. Public Perceptions of Research. 2024.
25. Fry A, Littlejohns TJ, Sudlow C, Doherty N, Adamska L, Sprosen T, et al. Comparison of Sociodemographic and Health-Related Characteristics of UK Biobank Participants With Those of the General Population. American Journal of Epidemiology. 2017;186(9):1026-34.
26. Investigators AoURP. The “All of Us” research program. New England Journal of Medicine. 2019;381(7):668-76.
27. Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA. The PCORI Engagement Rubric: Promising Practices for Partnering in Research. Ann Fam Med. 2017;15(2):165-70.
28. Unger JM, Hershman DL, Till C, Minasian LM, Osarogiagbon RU, Fleury ME, et al. "When Offered to Participate": A Systematic Review and Meta-Analysis of Patient Agreement to Participate in Cancer Clinical Trials. J Natl Cancer Inst. 2021;113(3):244-57.
29. Hau C, Efird JT, Leatherman SM, Soloviev OV, Glassman PA, Woods PA, et al. A Centralized EHR-Based Model for the Recruitment of Rural and Lower Socioeconomic Participants in Pragmatic Trials: A Secondary Analysis of the Diuretic Comparison Project. JAMA Netw Open. 2023;6(9):e2332049.
30. Jo G, Castro F, Cerilli C, Varadaraj V, Rosman L, Kamenov K, et al. Equitable inclusion of people with disabilities in clinical trials: a scoping review. BMJ Open. 2026;16(2):e108550.
31. Biggs K, Dix C, Shiely F, Treweek S, Shepherd V, Lane A, et al. Effective interventions to increase representation of under-served groups in randomised trials in UK and Ireland: a scoping literature review. NIHR Open Res. 2024;4:12.
32. GOV.UK. Population of England and Wales. 2024.