THE FREQUENCY OF EXCLUSION

1,204 community voices on clinical research in the United Kingdom

Equity Engine Community
A community powered by Unwritten Health

frequencyofexclusion.com

Contents

About this report

The Frequency of Exclusion is the first annual community landscape report from the Equity Engine community, brought to you by Unwritten Health. It is built on a single premise: health equity is a data infrastructure problem. Addressing it requires primary community data, not assumptions, proxies, or repackaged secondary research.

In March 2026, 1,204 people from underrepresented communities across the United Kingdom completed the Equity Engine Community Survey. They shared their experiences of healthcare, their relationship with clinical research, the barriers they face, the organisations they trust, and the conditions that would change their minds about participating in clinical trials.

This report presents those findings alongside analysis that is directly relevant to the clinical development organisations, pharmaceutical sponsors, and CROs responsible for designing and running the clinical trials that have, for too long, excluded these communities.

Who responded

1,204

TOTAL RESPONSES

UK-based community members completing the full survey in March 2026

63%

WOMEN

763 women, 519 men, 18 non-binary and prefer not to say respondents

55-64

LARGEST AGE GROUP

The most active survey demographic, reflecting the community health engagement profile

12

UK REGIONS REPRESENTED

Respondents from every major UK region, with intentional reach beyond London

Ethnic background

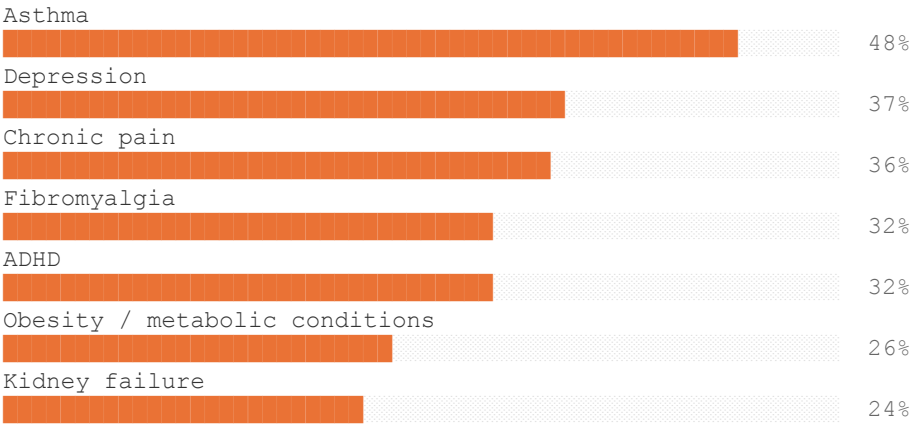
The survey was designed to reach communities chronically underrepresented in clinical research. Respondents identifying as Asian or Asian British (Chinese, Bangladeshi, Indian, Pakistani, and other Asian backgrounds) made up the largest proportion of the sample. Black or Black British respondents (Caribbean and African) were the next largest group. This distribution reflects the Equity Engine community's deliberate focus on the communities where the gap between population representation and clinical trial representation is most acute.

Geography

Respondents came from across the United Kingdom. The largest regional representation came from the East of England (214 respondents), North East (180), and North West (170). London had one of the smaller regional samples (61 respondents), reflecting the community's intention to surface voices from outside the capital, where most clinical research infrastructure is concentrated.

Health profile

763 respondents (63%) reported living with a long-term health condition or disability. The most commonly reported conditions were:



The conditions that dominate this list are invisible, contested, and stigmatised. Asthma. Depression. Chronic pain. Fibromyalgia. These are the conditions most likely to be under-diagnosed, undertreated, and dismissed by healthcare professionals. The communities living with them are the same communities being excluded from the clinical research that could help. This is the same finding, expressed twice over.

Executive summary

Four findings define this dataset. Each is significant in isolation, and together they describe a healthcare and research system that has structurally failed to earn the trust, engagement, or participation of communities that represent a growing proportion of the UK population.

Finding 1: 82% of this community have felt their health concerns dismissed

82% of respondents have felt their health concerns not taken seriously by a healthcare professional, occasionally or often. This is the dominant experience of the people in this survey and the root cause running beneath almost every other finding in this report. When eight in ten people from a community report being dismissed by the system designed to care for them, the consequence is a wholesale breakdown in the relationship between communities and clinical research. Clinical research begins with healthcare, and healthcare has already failed.

Finding 2: 83% would be more likely to participate in a co-designed clinical trial

83% of respondents said they would be more likely to participate in a clinical trial if it were designed specifically with their community in mind, by people who understood their lives. 45% said they would be significantly more likely. This is a direct, quantified case for community-first research design, and it is the most commercially significant finding in the dataset. The organisations that move earliest on this will have a structural recruitment advantage within three to five years.

Finding 3: Healthcare professionals are talking about clinical trials but communities are not understanding them

45% of all 1,204 respondents were told about a clinical trial by a healthcare professional and did not fully understand what they were being told. This is a communication failure at scale. Respondents with undergraduate degrees had the highest confusion rates (68%), above those with GCSEs (30%). The problem is the language of clinical research itself, which is opaque enough to confuse educated professionals and community members alike.

Finding 4: Structural barriers are the primary driver of exclusion, not trust

The clinical research industry has spent a decade treating diversity as a trust and communications problem. This data challenges that framing directly. The two most cited barriers to clinical trial participation are structural: too many hospital or clinic visits (628 responses) and clinical trials not being designed for people like the respondent (451 responses). Neither barrier can be addressed by better marketing. Both require redesigning how clinical trials are built and run.

> **"The same number of people named a barrier as named the solution."**
>
> 628 people cited too many hospital visits as a barrier. 476 people said a trusted community voice would make them more likely to participate. The gap between the problem and the fix is one of will, not evidence.

Section 1: Healthcare experience

Before communities can participate in clinical research, they must first trust the healthcare system that would refer them into it. The evidence from this survey suggests that trust has been comprehensively damaged, through the accumulation of everyday experiences of being dismissed, misunderstood, and deprioritised.

Being taken seriously

82%

HAVE FELT DISMISSED

Felt health concerns were not taken seriously by a healthcare professional, occasionally or often

12%

YES, OFTEN

Report being frequently dismissed, a consistent and repeated experience across multiple appointments

The distribution matters. 70% said they had felt dismissed occasionally, and 12% said it happened often. Only 15% said it had never occurred. The experience of being disregarded by healthcare is effectively universal in this community, and for 12%, the frequency is persistent enough to define their relationship with the system entirely.

The long-term consequence is not simply individual dissatisfaction. When communities learn that raising health concerns leads to dismissal, they adapt. They delay. They avoid. They manage conditions alone. They find informal support networks within their communities rather than returning to a system that has repeatedly failed them. The healthcare avoidance data in the following section is the direct downstream consequence of this finding.

> *"Trust has to be earned, not assumed. And right now, it has not been earned."*
> **Equity Engine community survey respondent**

> *"Past negative experiences affect willingness to engage. Once the system has let you down, you adapt."*
> **Equity Engine community survey respondent**

Healthcare avoidance

76%

AVOIDED HEALTHCARE

Avoided or delayed seeking healthcare in the past 12 months

94%

EAST OF ENGLAND

Highest regional avoidance rate, 18 points above the national average, the most significant geographic anomaly in the dataset

76% of all respondents avoided or delayed seeking healthcare in the past twelve months. That figure represents a rational response to a system that has consistently failed to serve these communities well. When seeking care becomes too costly in time or resource, too painful in terms of

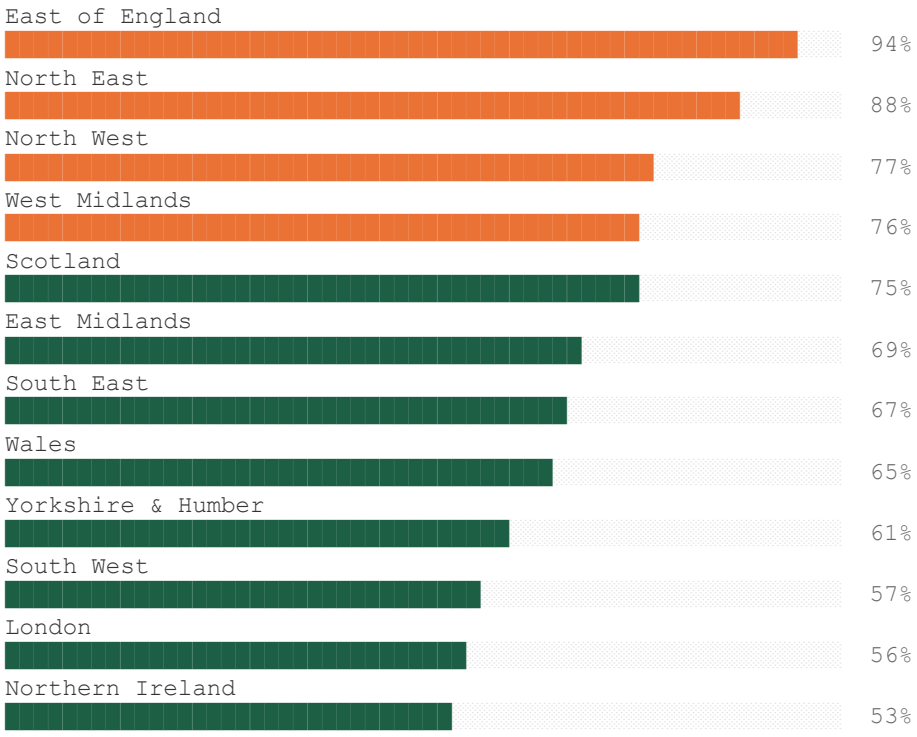
the dismissal it regularly produces, or too uncertain in terms of whether it will lead anywhere productive, many people make the entirely logical decision to manage on their own.

The consequences compound over time. Conditions that could have been managed early progress to more serious presentations. Medication goes unreviewed. Preventable hospital admissions accumulate. For the NHS, the economics are clear: avoidance in primary care generates significantly higher costs downstream through emergency and secondary care. For clinical research, the implications are more direct: communities that have disconnected from primary care are communities that will never be referred into clinical trials. The clinical trial participation pipeline does not exist for them.

This is why the healthcare avoidance finding belongs at the centre of any strategy for improving clinical trial diversity. It is not a separate problem. It is the same problem, one step earlier in the pathway. Improving clinical trial diversity without addressing healthcare avoidance is building on sand.

Regional variation

Healthcare avoidance is not a national average. It is concentrated geographically, and the pattern of that concentration matters:



The East of England presents as a genuine statistical outlier at 94%, eighteen percentage points above the national average and thirty-eight points above London. This is the region that hosts the fewest clinical trial sites relative to population, where GP access is most stretched outside the major cities, and where community infrastructure is thinnest. London's lower rate (56%) likely reflects greater access to healthcare infrastructure, higher concentration of community organisations, and more visible clinical research presence in the city. The distance between these two regions describes two entirely different healthcare realities coexisting within the same national system.

> *"The healthcare system works for some people. For communities like ours, it is something we navigate around."*
>
> **Equity Engine community survey respondent**

Section 2: Clinical trial awareness and participation

Clinical trial participation in this survey is higher than general population benchmarks, a function of the Equity Engine community's deliberate reach into engaged community networks. The more important data is the variation between communities, the conditions under which participation occurs, and the persistent structural gaps that even motivated communities cannot always overcome.

Awareness

36%

FIRST HEARD HERE

426 respondents had never heard of clinical trials before completing this survey

28%

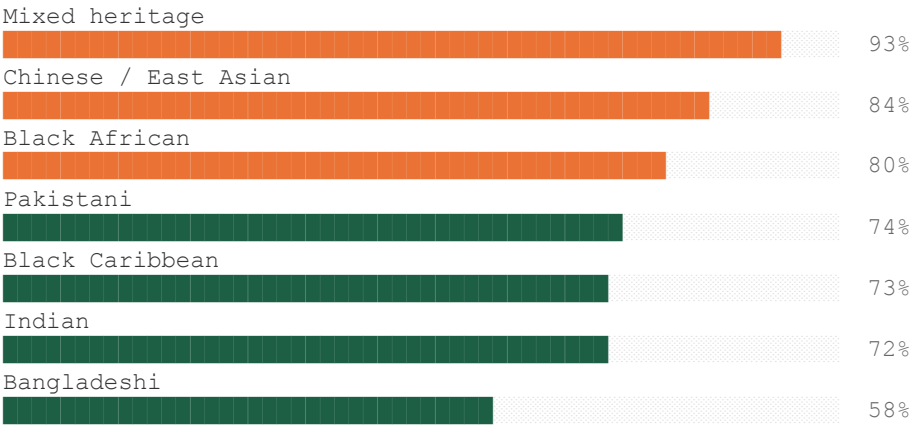
ALREADY KNOWLEDGEABLE

435 respondents described themselves as already well-informed about clinical trials

More than a third of respondents had never heard of clinical trials before this survey. Awareness is the first barrier, and it falls before trust, logistics, or language. The communities least likely to be aware are typically those most likely to be living with the conditions that are underrepresented in clinical trial data. The industry routinely treats diversity as a recruitment problem, when it is frequently an awareness problem that comes earlier in the pipeline.

Participation by ethnic background

Clinical trial participation rates vary significantly across ethnic groups within the survey. The variation itself is the primary finding:



Bangladeshi respondents have the lowest clinical trial participation rate in the sample at 58%, a 35-point gap compared to Mixed Heritage respondents. This sits alongside a pattern that connects multiple findings. Bangladeshi respondents report high levels of caring responsibilities, above-average rates of healthcare avoidance, and strong representation among the conditions (asthma, kidney failure, diabetes-related conditions) that are both prevalent in South Asian communities and chronically underrepresented in clinical trial data.

The barriers they name are overwhelmingly structural: too many hospital visits, caring responsibilities, clinical trials not designed for people like them. These are the same top-two structural barriers that define the dataset as a whole, but they land with particular weight in this community. A clinical trial designed with flexible scheduling, remote participation options, and

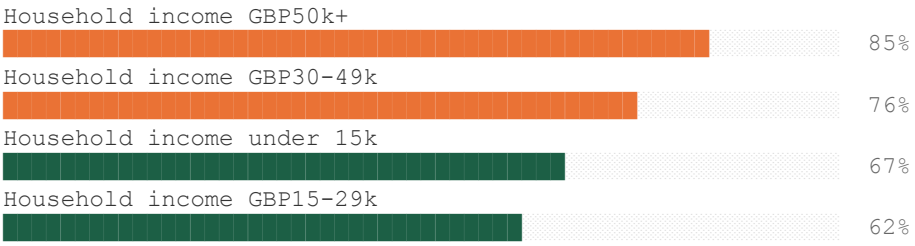
community organisation partnerships would directly address the reasons Bangladeshi clinical trial participation lags. This is a design problem requiring a structural response.

Bangladeshi participation: a structural case study

Lowest clinical trial participation rate in the dataset (58%). Top barriers: too many hospital visits, caring responsibilities, not designed for someone like me. The data supports a structural redesign of how clinical trials are built and where they are run. Remote participation and community organisation partnerships are the specific interventions indicated.

Participation by income

A clear income gradient runs across clinical trial participation rates:



Clinical trial participation rises sharply with household income. The top three barriers (too many hospital visits, caring responsibilities, and the cost of participation in time and money) are all more acute for lower-income households. Remote participation options, named by 443 respondents as an enabler, are the most direct lever to close this gap.

The HCP communication gap

45%

TOLD BUT DID NOT UNDERSTAND

Were told about a clinical trial by a healthcare professional and did not fully understand what they were being told

68%

GRADUATE CONFUSION RATE

Undergraduate degree holders were the most confused group in the dataset, above respondents with GCSEs or no formal qualifications

45% of all 1,204 respondents were told about a clinical trial and left the conversation without understanding what they had been offered. This is a communication failure happening at scale, right now, in GP surgeries and hospital outpatient departments across the UK. The graduate confusion finding (68%) is the most counterintuitive data point in this report. The problem is the specialised language of clinical research, which is opaque enough to confuse educated professionals. Plain-language communication is a universal standard, not a targeted intervention for specific literacy levels.

> *"Language barriers can make it hard to fully understand medical information and consent forms. And I am not talking about English. I am talking about jargon."*
>
> **Equity Engine community survey respondent**

Section 3: Trust in health research organisations

Mean trust scores for all six organisations sit between 2.99 and 3.41 out of 5, a range that looks broadly moderate. The mean is not the finding. The distribution is. Almost every institution divides communities sharply: a large group trusting, a large group distrusting, with relatively few in the middle. This polarisation is the defining feature of how communities relate to health research institutions.

The exception is university researchers. Where NHS and GP scores show high variation (deeply divided opinions), university researchers have the lowest variation in the dataset. 621 out of 1,204 respondents rated them as 3 out of 5. Communities are not distrusting of university researchers. They are indifferent to them. The relationship has not been damaged. It has simply not been built.

Trust scores and distribution

Organisation	Mean /5	1 Low	2	3 Neutral	4	5 High	Finding
Community orgs	**3.41**	62	82	154	183	265	*Most trusted*
Pharma companies	**3.39**	98	124	152	187	245	*Polarised*
GP	**3.21**	112	178	145	198	241	*Mixed*
University res.	**3.05**	89	142	621	102	51	*Indifferent*
NHS	**3.04**	158	182	145	198	182	*Polarised*
Charities	**2.99**	82	298	412	248	42	*Wary*

Reading the polarisation

The NHS at 3.04 tells a story the mean obscures: roughly equal proportions rating it 1 (deep distrust, 158 people) and 5 (high trust, 182 people), with the rest distributed across the middle. This is a divided community, carrying divided histories of the same institution. The GP score (3.21) shows similar polarisation. Community organisations (3.41) have the highest mean but are also divided: 265 people rated them 5, but 62 rated them 1. Even the most trusted institution in this dataset divides communities.

Why pharmaceutical companies score higher than the NHS: an interpretation

The pharmaceutical company score (3.39) sits above the NHS (3.04) in this dataset, which is counterintuitive when set against published research on institutional trust. Several factors are likely at work and are worth naming directly.

First, the survey question asked respondents to rate each organisation on whether they act in their best interest for health research. Many respondents in this community are living with long-term conditions and are medication-dependent: asthma, chronic pain, kidney failure. Their lived experience of pharmaceutical products is that those products manage their conditions and keep them well. The question may have activated this relationship with pharmaceutical products rather than a view about pharmaceutical companies as clinical research institutions.

Second, community knowledge of pharmaceutical companies as clinical research actors is relatively low. 152 respondents rated pharmaceutical companies as 3 (neutral), suggesting that a meaningful proportion of the apparent trust is in fact the absence of a formed opinion. This mirrors the university researcher indifference finding: communities do not know enough to form a strong view.

Third, the polarisation in the pharma score is wide (98 rating 1, 245 rating 5). The group rating pharma highly is large, and it likely includes respondents whose primary experience of the pharmaceutical industry is as a provider of medicines that have improved their quality of life. The group rating pharma at 1 (98 respondents) is also significant and likely reflects awareness of historical harms and commercial interests in clinical research design.

A finding to hold carefully

The pharmaceutical company trust score in this dataset reflects communities' relationship with pharmaceutical products, not necessarily their confidence in pharmaceutical companies as clinical research actors. Disaggregated follow-up questions in Vol. 2 of this survey will distinguish between these two relationships. This finding should be read as contextual, requiring further investigation, rather than as a straightforward endorsement of the sector's trustworthiness as a clinical research partner.

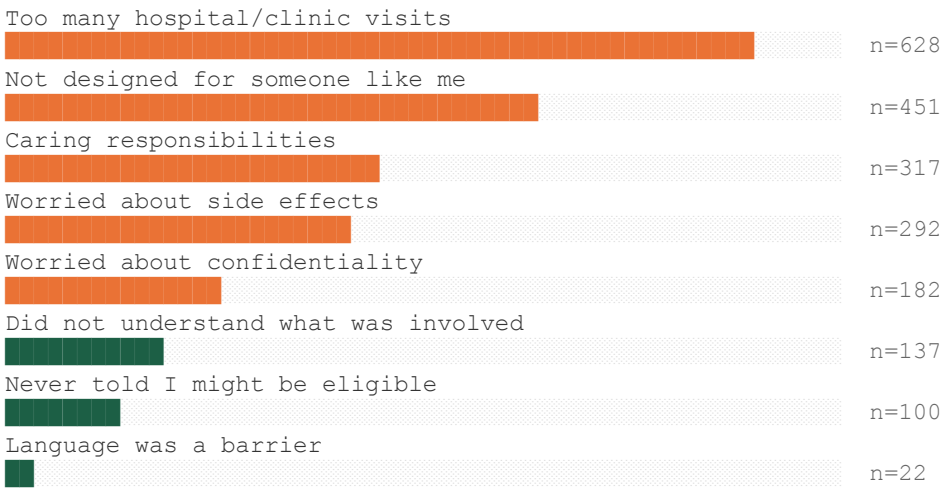
The institutions running most clinical trials (universities and the pharmaceutical companies sponsoring them) sit at the bottom or middle of this trust table. Community organisations, which run almost no clinical research, sit at the top. The pathway to improved diversity in clinical research therefore runs through the most trusted institutions. This is a partnership model, and the data makes clear who the partners need to be.

Section 4: Barriers and enablers

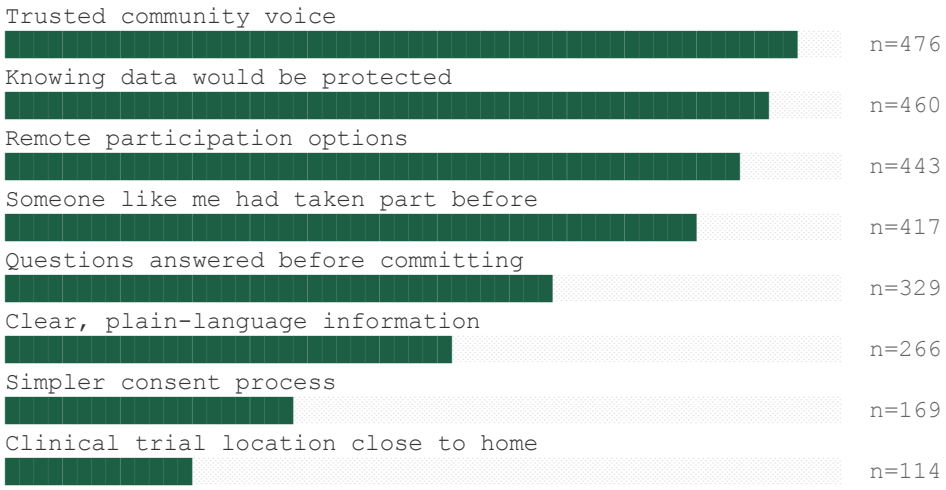
The clinical research industry has, for many years, centred its diversity strategy on trust. Communities distrust research. The solution has been framed as communications: better messaging, improved consent processes, more culturally sensitive outreach. This data complicates that narrative significantly.

The top two barriers to clinical trial participation in this dataset are structural. They are about logistics and design. They are about a clinical trial infrastructure built around a specific type of participant (broadly: white, male, employed, mobile, with no caring responsibilities) that has never been fundamentally redesigned to accommodate anyone else. The third and fourth barriers (side effects and confidentiality) have a trust dimension, but they come third and fourth. The sector has been solving for third-place problems while first-place problems go unaddressed.

What stops people



What would change that



The symmetry finding

628 people named too many hospital visits as a barrier. 443 named remote participation as an enabler. These are the same constraint, seen from two directions. The barrier is physical infrastructure. The solution is redesigning that infrastructure. This is an operational change, not a communications change.

476 people named a trusted community voice as the enabler most likely to change their mind. The figure for the top barrier (628) is within range of this number. The community has told us the solution is as large as the problem. What is needed is the will to deploy it.

> *"Being told by a trusted person or organisation in my community would make all the difference. I do not need to be convinced by a researcher. I need to hear it from someone who knows my life."*
>
> **Equity Engine community survey respondent**

The designed-for-me paradox

99% of respondents who said clinical research is designed for people like them still cited barriers to clinical trial participation. Feeling represented in research and being able to participate in clinical trials are entirely separate problems. The barriers are practical, logistical, and structural. Addressing clinical trial diversity through communications while leaving the underlying design unchanged will produce marginal results.

The central campaign argument

The two most cited barriers to clinical trial participation are structural, about logistics and design. The industry has spent a decade treating diversity as a trust problem requiring a communications solution. This data shows it is a structural problem requiring an operational solution. Redesigning clinical trials around community realities (remote participation, flexible scheduling, community organisation partnerships) is a more direct intervention than any amount of improved messaging.

Section 5: What communities say

747 respondents gave substantive answers to the question: what is the one thing you wish clinical researchers understood about your community? Seven themes dominate. These are their words.

Theme 1: Trust must be earned, not assumed

The most common theme in open-text responses is trust, specifically its absence and what it would take to rebuild it. Respondents frame this as work that researchers have consistently failed to do.

> *"Trust is not automatic in my community. It has to be earned through honesty, through consistency, and through showing up, not just when you need data from us."*
> **Equity Engine community survey respondent**

> *"Trust in the healthcare system is not always high due to past experiences or discrimination. This has to be named, not avoided."*
> **Equity Engine community survey respondent**

Theme 2: Practical barriers are invisible to researchers

Respondents consistently name barriers that are visible in their daily lives but invisible to clinical trial designers: time, transport, caring responsibilities, cost. These are structural facts that clinical trials are built around the assumption that people do not have.

> *"Practical issues like time, cost, and travel can stop people from taking part. Researchers do not always see what clinical trial participation actually costs us in real life."*
> **Equity Engine community survey respondent**

Theme 3: Awareness is still the first problem

Before trust, logistics, or language, there is simply not knowing. A significant proportion of respondents describe discovering clinical trials for the first time through this survey. For them, the question of clinical trial participation had never arisen because the option had never been presented.

> *"There is a lack of awareness about clinical research in our community. People want to know how it benefits them directly, not what it does for science in general."*
> **Equity Engine community survey respondent**

Theme 4: Culture shapes health decisions in ways researchers do not account for

Health decisions are not made in isolation. Family structures, cultural beliefs, and community norms shape how people approach healthcare and clinical research. Respondents describe a clinical research system that treats participants as individuals and misses the relational and cultural context in which health decisions are actually made.

> *"Cultural beliefs and family influence play a big role in how people approach healthcare. A researcher talking to one person is often talking to a whole family's decision."*
> **Equity Engine community survey respondent**

Theme 5: Community must be involved in design, not just recruited for

Respondents distinguish between being recruited into a clinical trial (which they experience as extractive) and being involved in designing it (which they describe as the condition under which genuine clinical trial participation becomes possible).

> *"Building real relationships with communities matters more than one-off engagement. We want to be involved from the beginning."*
> **Equity Engine community survey respondent**

> *"People want to see people like them involved, not just in the leaflet, but in the room where decisions are made."*
> **Equity Engine community survey respondent**

Theme 6: Language is a barrier that goes beyond translation

Respondents describe a language barrier that is primarily about the language of clinical research itself, consent forms, study protocols, medical terminology, rather than English proficiency. This connects directly to the 45% HCP communication finding: the confusion happens in English, with English-speaking professionals, because clinical research has developed a vocabulary that excludes the people it is trying to recruit.

> *"Language barriers can make it hard to fully understand medical information and consent forms. And I am not talking about English. I am talking about jargon."*
> **Equity Engine community survey respondent**

Theme 7: Fear of being treated as a subject, not a person

A recurring concern runs through the responses: that clinical research treats community members as a resource to extract data from, rather than people to involve in a shared endeavour. This concern has a history, and respondents are clear that it requires acknowledgement before reassurance.

> *"Many people fear being treated like test subjects. That fear does not come from nowhere. It comes from what has actually happened to communities like ours."*
> **Equity Engine community survey respondent**

Section 6: The co-design uplift

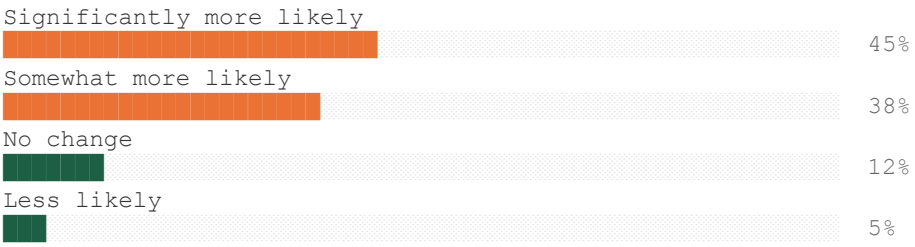
When asked whether they would be more likely to participate in a clinical trial designed specifically with their community in mind, by people who understood their lives, respondents answered decisively.

83%

WOULD BE MORE LIKELY TO PARTICIPATE IN A CLINICAL TRIAL

if the clinical trial were co-designed with their community

Breakdown



45% would be significantly more likely to participate in a clinical trial. 38% would be somewhat more likely. 83% combined represents a decisive behaviour-change signal. This is the number that belongs at the centre of any business case for community-first clinical research design.

The commercial logic is straightforward. Clinical trial recruitment is one of the most significant cost and timeline drivers in drug development. Delays in recruitment extend development timelines and increase costs across the entire programme. If co-designing clinical trials with community organisations increases participation likelihood for 83% of underrepresented communities, the return on investment in community engagement is an operational question, and the answer is clear.

The sectors that will benefit most are those where clinical trial recruitment diversity is already a regulatory requirement, or where it is becoming one. The organisations that build community co-design capability now will have a structural advantage when those requirements arrive.

Co-designing clinical trials with communities is an operational strategy with a measurable return.

83% of respondents would be more likely to participate. 45% would be significantly more likely. The organisations that move first will have a structural clinical trial recruitment advantage as regulatory requirements tighten.

Section 7: Outliers and anomalies

Several findings in this dataset deviate significantly from expected patterns. Each changes how the headline data should be read, or points toward an area requiring further investigation in future survey waves.

The East of England: 94% healthcare avoidance

Every other UK region sits between 53% and 88% for healthcare avoidance. The East of England is at 94%, eighteen percentage points above the national average. Contributing factors are likely to include rural isolation, limited GP access outside major urban centres, lower concentrations of community organisations, and specific community demographics in the region. A targeted follow-up study in the East of England is warranted before Vol. 2, to establish whether this is a stable structural finding or a sampling artefact.

55 to 64 year olds have the highest clinical trial participation rate (88%)

The 55 to 64 age group participates in clinical trials at 88%, the highest rate in the dataset. This group typically faces more structural barriers than younger respondents. The likely explanation is that this group has the highest prevalence of long-term conditions, giving them more touchpoints with the healthcare system and more direct motivation for clinical research engagement. This points toward an underutilised peer advocacy opportunity: structured programmes that train and deploy 55 to 64 year old participants as community champions for clinical trial participation would directly activate the trusted community voice enabler cited by 476 respondents.

People who feel clinical research is not designed for them have higher participation

Respondents who feel clinical research is not designed for them have a clinical trial participation rate of 95%, higher than those who feel it is designed for them (66%). People who have already participated in clinical trials know from direct experience that clinical trials are not designed for them. Their participation was achieved despite exclusion. The system is relying on motivated individuals to overcome structural barriers, and this is not a sustainable diversity strategy.

Undergraduate degree holders are most confused by HCP explanations

68% of respondents with undergraduate degrees did not fully understand what a healthcare professional told them about clinical trials, above respondents with GCSEs (30%) or no formal qualifications (46%). The problem is the specialised vocabulary of clinical research, which creates confusion that is independent of general educational attainment. Plain-language standards should be universal.

36% of respondents are currently in a clinical trial

430 respondents (36%) are currently enrolled in a clinical trial. This is high for any survey, and particularly so for one targeting communities that face structural barriers to clinical trial participation. It confirms that the Equity Engine sample is a highly engaged community panel, and that headline participation rates should be understood in this context.

Section 8: Recommendations

The following seven recommendations are grounded in what communities told us in March 2026. Each names the specific data point that motivates it, the action required, who needs to act, and what the expected outcome is.

1. Treat structural barriers as the primary design problem

EVIDENCE BASE: 628 RESPONSES (TOO MANY VISITS), 451 RESPONSES (NOT DESIGNED FOR ME)

The two most cited barriers to clinical trial participation are structural. Every new clinical trial protocol should include a structural access review at design stage, before clinical trial recruitment opens. The review should address: scheduling flexibility (can appointments be outside working hours?), location (can any element be delivered remotely or in community settings?), and visit burden (what is the minimum number of in-person visits required, and has that minimum been challenged?).

Who needs to act: Sponsors and CROs at protocol design stage, regulatory advisors with responsibility for feasibility review.

Expected outcome: Measurable reduction in the top two cited barriers within two to three clinical trial cycles for organisations that adopt this as standard practice.

2. Make remote participation the default, not an accommodation

EVIDENCE BASE: 443 RESPONSES (REMOTE PARTICIPATION ENABLER), 628 RESPONSES (VISIT BURDEN BARRIER)

Remote clinical trial participation options (video consultations, home sample collection, digital data submission) should be the default design choice for any clinical trial element that does not require in-person clinical assessment. The burden of justification should fall on in-person requirements, not remote alternatives. Protocols requiring in-person attendance for all visits should require explicit justification at ethics review stage.

Who needs to act: Sponsors, CROs, ethics committees, site management organisations.

Expected outcome: Improved clinical trial participation rates among lower-income, higher-caring-responsibility, and more geographically dispersed community groups.

3. Fund community organisations as primary clinical research infrastructure

EVIDENCE BASE: COMMUNITY ORGANISATIONS MOST TRUSTED AT 3.41/5, 476 RESPONSES (TRUSTED COMMUNITY VOICE)

A defined proportion of clinical trial recruitment budgets should be allocated to partnerships with community organisations, as primary clinical trial recruitment channels rather than distribution points for existing communications. Community organisations should be involved in participant identification, relationship building, and ongoing clinical trial support, with fair payment, shared data access, and involvement in reporting.

Who needs to act: Sponsors and CROs with responsibility for clinical trial site selection and recruitment strategy, patient engagement teams within pharma and biotech organisations.

Expected outcome: Access to the community trust networks that 476 respondents identified as the primary enabler of clinical trial participation. Improved clinical trial recruitment rates in underrepresented populations.

4. Redesign informed consent as a communication process, not a document

EVIDENCE BASE: 45% OF RESPONDENTS TOLD ABOUT CLINICAL TRIALS AND DID NOT UNDERSTAND, 68% GRADUATE CONFUSION RATE

Current consent documentation across all active clinical trials should be audited against plain-language standards. New consent processes should include a comprehension check before consent is given, plain-language summaries should be co-developed with community organisations, and visual or video formats should be available as alternatives to text-only documents. Consent should be treated as a process of genuine understanding, not a signature obtained.

Who needs to act: Sponsors and CROs with responsibility for clinical trial documentation, regulatory affairs teams, ethics committees.

Expected outcome: Reduction in the 45% comprehension failure rate. Improved informed consent quality with downstream benefits for clinical trial protocol adherence, retention, and participant safety.

5. Make data protection commitments explicit and early

EVIDENCE BASE: 460 RESPONSES (DATA PROTECTION ENABLER), CONFIDENTIALITY CITED AS FIFTH MOST COMMON BARRIER

In all community-facing communications about clinical trials, data protection commitments should be named explicitly in the first communication, in plain language, in a dedicated section. This applies to clinical trial recruitment materials, HCP conversations, consent documentation, and digital platforms. The commitment should describe specifically what data is collected, who has access to it, how long it is retained, and what rights participants have.

Who needs to act: Sponsors, CROs, clinical trial sites, and community organisations involved in participant-facing communications.

Expected outcome: Reduction in the confidentiality barrier. Improved clinical trial recruitment conversion rates among respondents who name data protection as a condition of participation.

6. Prioritise outreach in East of England and North East

EVIDENCE BASE: EAST OF ENGLAND 94% AVOIDANCE, NORTH EAST 88% AVOIDANCE

Geographic allocation of community engagement budgets should be weighted toward these regions in the next two years. This includes investment in community organisation partnerships, mobile or remote clinical trial participation infrastructure, and GP and primary care engagement to improve clinical trial referral rates. A specific follow-up survey wave targeting East of England respondents should be run ahead of Vol. 2 to establish whether the 94% avoidance figure is a stable structural finding.

Who needs to act: Sponsors and CROs selecting clinical trial sites, NHS integrated care boards in these regions, Equity Engine community outreach teams.

Expected outcome: Better understanding of the drivers of the East of England anomaly. Improved community presence in regions with the highest unmet need and the lowest current clinical research engagement.

7. Deploy the 83% co-design statistic as a commercial argument

EVIDENCE BASE: 83% MORE LIKELY WITH CO-DESIGNED CLINICAL TRIAL, 45% SIGNIFICANTLY MORE LIKELY

This statistic should be incorporated into every business case for community engagement investment, every pitch to a Clinical Operations or Medical Affairs team, every conference presentation on clinical trial diversity, and every regulatory submission addressing diversity action

plans. The data makes the commercial case for co-design. The sector needs to hear it made in commercial terms, with a number attached.

Who needs to act: Unwritten Health and Equity Engine partners, clinical operations leaders in pharma and biotech, patient engagement teams, regulatory affairs professionals preparing diversity action plans.

Expected outcome: Accelerated adoption of community co-design as a standard element of clinical trial design. The organisations that adopt co-design earliest will have a structural clinical trial recruitment advantage as mandatory diversity requirements arrive.

Methodology

Survey design

The Equity Engine Community Survey was designed by Unwritten Health in consultation with community advisors. The survey comprised 49 questions covering demographic information, healthcare experience, clinical trial awareness and participation, trust in health research organisations, access and logistics, and open-text responses.

Data collection

The survey was distributed digitally via Equity Engine community networks in March 2026. 1,204 respondents completed the survey in full. The sample was designed to reach communities chronically underrepresented in UK clinical trial data.

Sample context

The Equity Engine sample is a self-selected, community-engaged panel. Respondents are more likely to be actively engaged with health issues and community organisations than the general underrepresented population. Headline clinical trial participation rates are higher than general population benchmarks and should be understood as community-engaged sample data. The variation between groups and the barriers and enablers respondents name are the primary signal for research purposes.

Open text analysis

All responses were anonymised before analysis. Open-text responses shorter than 15 characters, or comprising null responses, were excluded from thematic analysis. 747 substantive open-text responses were included. Thematic categories were identified through iterative keyword analysis across the full corpus.

Limitations

The survey was conducted in English only. Language barriers may have limited participation from communities for whom English is not a primary language, consistent with the language barrier cited by 22 respondents in the barriers data. Sample sizes for some ethnic subgroups (Pakistani, n=73; Black African, n=54) are relatively small for subgroup analysis and should be treated as directional pending larger samples in future waves.

This is Vol. 1

The Frequency of Exclusion is an annual report. Vol. 1 presents findings from 1,204 community members surveyed in March 2026. The target for Vol. 2 is 5,000 respondents, a sample large enough to support robust subgroup analysis by region, ethnicity, income, condition type, and trust profile.

Every finding in this report will be updated as the community grows. Community members who want to be part of the next wave can complete the survey and join the Equity Engine community at frequencyofexclusion.com.

Equity Engine Community

A community landscape report brought to you by Unwritten Health

frequencyofexclusion.com