Perceptions & Insights Study

2025

Global trends in public and patient attitudes about, and experience with, clinical research

ENGAGEMENT PREFERENCES

Introduction

Supportive services and flexible study visit options continue to play a critical role in improving access to clinical research studies, particularly among underrepresented communities.

In this report, CISCRP highlights engagement preferences for participation in clinical research studies. These findings identify important elements of participation, as well as provide a comprehensive view of receptivity to various decentralized clinical research models. The insights can help inform the design and optimize the implementation of these clinical research studies.

ENGAGEMENT PREFERENCES

Overall, it was 'very important' to respondents to receive **supportive information about managing their health condition** and **regular updates from the study**.

The top-rated drivers to staying enrolled in a clinical study were **seeing benefit from the study drug, receiving compensation,** and **conveniently located study visits**.

Over 90% are 'somewhat' or **'very comfortable'** sharing various types of health data via **wearable devices**, but **comfort levels with sharing cell phone data are not as high**.

Respondents had a **strong interest** in **receiving their own individual results** (e.g., blood tests, imaging, and genetic testing), as well as **overall study results**.

Supporting Information and Study Updates Continue to be Very Important to Participation

Imagine you were to participate in a clinical research study, how important are the following to your participation?
% indicating 'Very Important'

Supporting information on managing my health condition in general	**49%**
Regular study updates	**47%**
Supportive services	**46%**
The opportunity to provide feedback on your experience participating in a clinical research study	**46%**
Supporting information on the clinical research study	**44%**
Some or all study visits conducted at my home or a location convenient to me	**42%**
Study information designed specifically for caregivers/family	**29%**

Sample Size = 8,472 | Base: Those who never participated in a clinical study, 2025

Most preferred (74%) to be contacted via email during participation.

Those who were **Black/African American** were **most likely to place high importance** on each of these supporting services/ resources.

Women were **more likely than men to place high importance** on each of these services/resources.

Findings are **generally consistent** with previous years.

Comfort Levels with Decentralized Clinical Study Elements Remain Generally High

Imagine you were to participate in a clinical research study, <u>how comfortable</u> (if at all) would you be with each of the following? *% indicating 'Very Comfortable'*	
Having study visits at your regular doctor's office	**54%**
Conducting simple medical assessments on your own at home	**49%**
Using a wearable device	**44%**
Having study visits at a local lab	**42%**
Speaking with the study doctor via video conference	**42%**
Completing a patient diary and regularly tracking symptoms, diet, medications, etc.	**41%**
Having a nurse come into your home for study visits	**40%**
Having study visits at your local community health clinic	**39%**
Having study visits at a mobile clinic/ mobile health unit	**33%**

Sample Size = 8,472 | Base: Those who never participated in a clinical study

In general, **highest comfort levels in Africa** and **North America**, and **lowest comfort levels in Asia**.

Those with a **higher education level indicated greater levels of comfort**.

Those with a **medical condition indicated higher comfort levels** compared to those **without a medical condition**.

Those with a medical condition in the **rare disease, autoimmune, and oncology** treatment areas indicated the **greatest level of comfort** with completing **simple medical assessments on their own at home**.

Key Retention Factors

Respondents were asked to rank these items starting with the items that would be **most likely to keep them enrolled in a clinical research study until the end** (i.e., not drop out) and ending with the item that would be least likely to keep them enrolled.

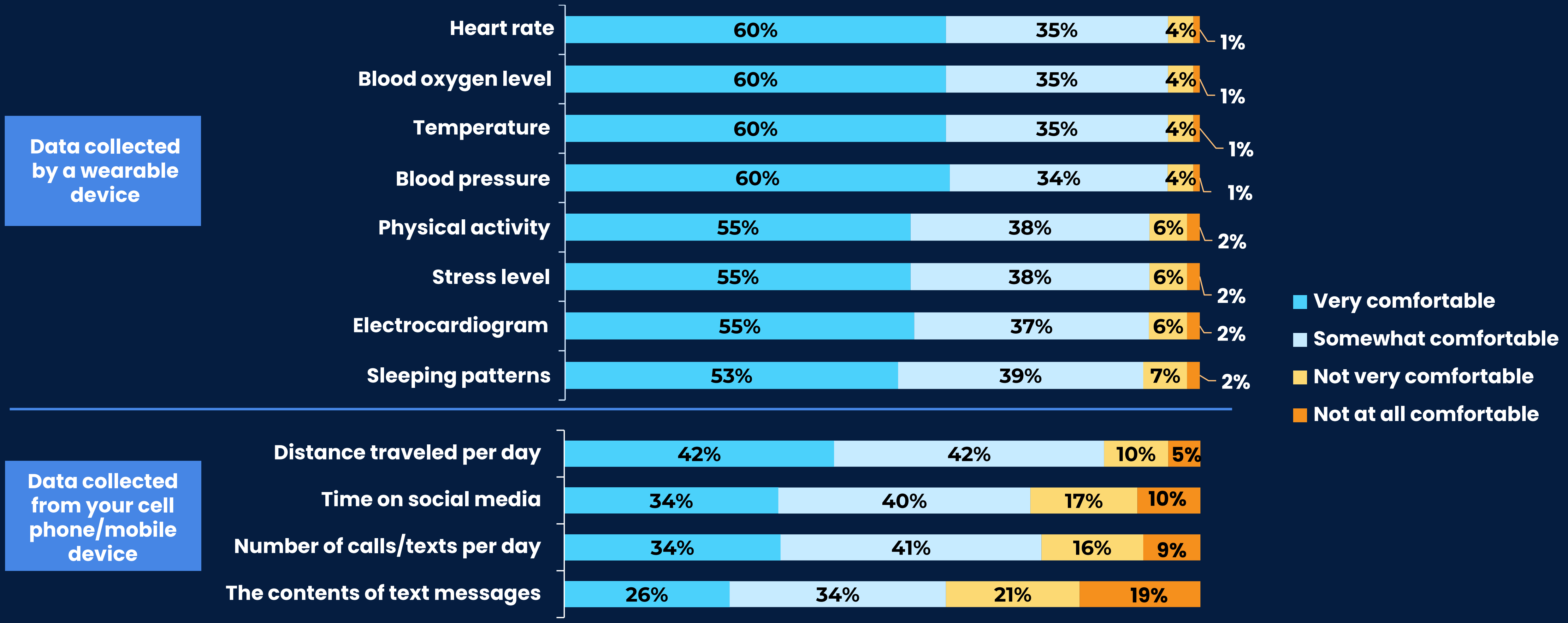
After feeling/seeing benefit from the study drug, top retention strategies were related to **providing compensation and reimbursement**, **reducing logistical burdens** by offering local study visits, and having the ability to **view medical test results**.

		2025 (mean score)
1	Feeling/seeing benefit from the study drug	4.44
2	Receiving compensation for my time	4.89
3	Having the ability to complete study visits closer to my home	5.29
4	Being able to see my own medical test results	5.41
5	Reimbursing any out-of-pocket expenses	5.43
6	Having study visits with flexible times	5.57
7	Being informed of the clinical research progress on a regular basis	5.69
8	Building relationships with the study staff	6.25
9	The ability to have my study visits at home rather than traveling to a study clinic	6.30
10	Having transportation provided to me to/from the study clinic	7.04
11	Having childcare available	9.72

Sample Size = 12,887 | Base: All respondents

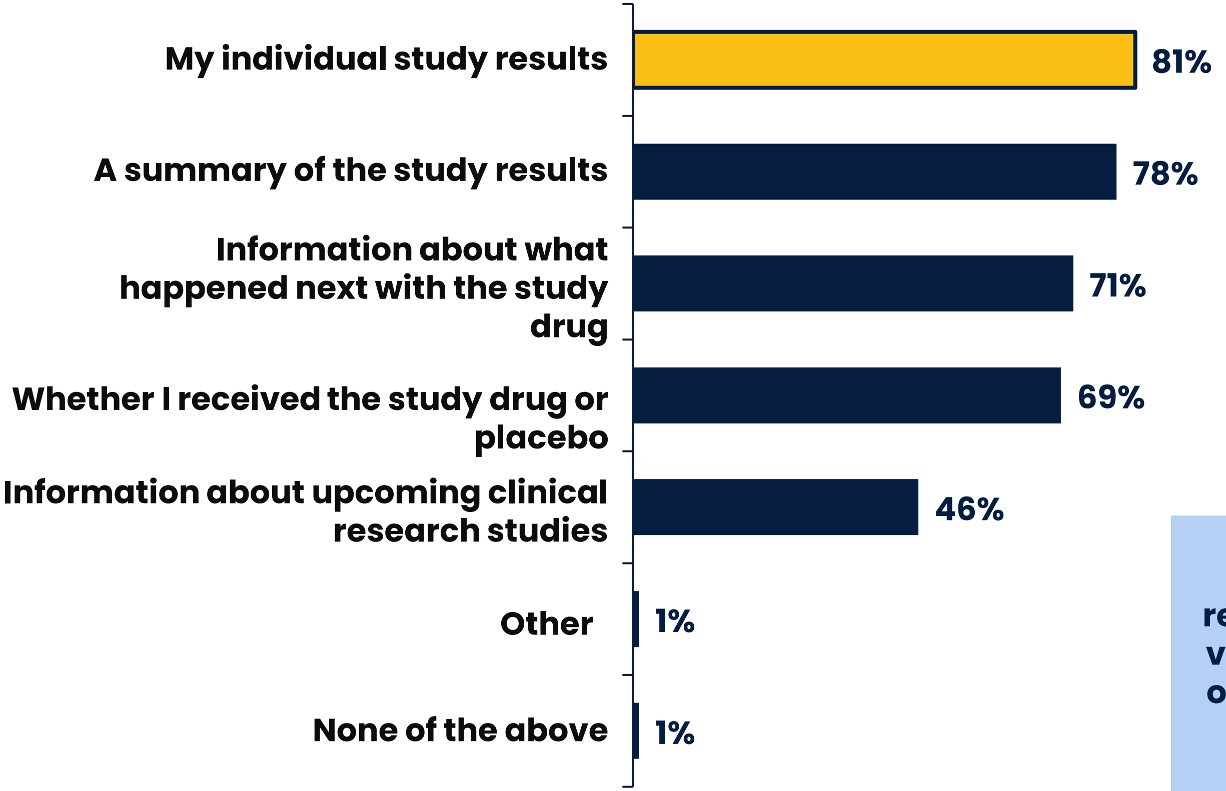
Higher Comfort Sharing Data from Wearable Devices Compared to Smartphones

How comfortable are you sharing each of the following types of data as part of your participation in a clinical research study?



Strong Interest in Receiving Individual and Overall Study Results

What information would you be most interested in receiving after completing your participation in a clinical research study?
(Select all that apply)



Sample Size = 12,887 | Base: All respondents, 2025

Most preferred to receive study results via email (71%) or an online patient portal (49%).

What kind(s) of individual study results would you be most interested in receiving?
(Select all that apply)

- **Blood tests (85%)**
- **Imaging results** (e.g., CT scans, PET scans) **(80%)**
- **Genetic test results (78%)**
- **Vitals** (e.g., blood pressure, heart rate) **(70%)**
- **Doctor visit notes (63%)**

Sample Size = 10,427 | Base: Those who selected 'individual study results' for information they would be most interested in receiving after completing their participation in a clinical research study.
Note: 2% indicated 'Other'

About this Study

The objectives of this study are to establish routine global assessments of public and patient perceptions, motivations, and experiences with clinical research in order to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in the clinical research enterprise.

Between April and June 2025, CISCRP conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CISCRP received input and support from pharmaceutical, biotechnology, and contract research organizations. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, and Rare Patient Voice to reach and engage respondents.

12,887
Survey Respondents

Respondent characteristics are as follows:

Gender	53% Female | 46% Male | 1% All other genders
Region	44% North America | 5% South America | 41% Europe | 5% Asia-Pacific | 5% Africa
Age	18% 18–34 years old | 16% 35–44 years old | 16% 45–54 years old | 20% 55–64 years old | 31% 65 or older
Race (top mentions)	76% White | 9% Black or African-American | 6% Asian
Ethnicity	86% Non-Hispanic | 13% Hispanic
Incidence of participation in a clinical study	66% have never participated | 34% have participated

Note: Percentages throughout this report may not total 100 due to rounding

The Center for Information and Study on Clinical Research Participation (CISCRP) is an internationally recognized non-profit organization dedicated to educating and informing the public and patients about clinical research. CISCRP works to raise awareness, enhance experiences, and strengthen communication and relationships among participants, research professionals, and the public through various services and events.

About CISCRP's Research Services

- ✓ ***Patient & Caregiver Advisory Boards***
- ✓ ***Clinical Trial & Patient Journey Projects***
- ✓ ***Surveys & Quantitative Research Projects***
- ✓ ***Custom Research Projects***

CISCRP's experienced Research Services team is skilled at engaging patients and their support network to obtain meaningful insights for sponsors — including pharmaceutical, biotechnology and medical device companies; contract research organizations; academic and for-profit institutions; foundations; and nonprofit organizations.

Recognized as a trusted leader in the industry, our team brings extensive global experience across therapeutic areas. We excel at facilitating discussions on complex concepts, therapies, and protocols with patients and the public. The findings gathered are transformed into actionable insights designed to drive organizational change.

2025 Perceptions and Insights Study Team

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CISCRP

Thank You

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JLC James Lind Care.
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